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ABSTRACT

This study aims to understand the special needs of Asian Americans with developmental disabilities living in the Chicago (Illinois) metropolitan area. Findings are intended to help service delivery systems meet the needs of this population through culturally effective services. The study acknowledges that there are differences among Asian ethnic subcultures, but assumes that the common aspects of Asian cultures allow a general understanding of the needs of Asian Americans with developmental disabilities. Background information on Asian Americans in the Chicago area is supplemented by a survey of mainstream social service providers, which was completed by representatives of 44 agencies. Thirty-two of these agencies reported serving Asian Americans with developmental disabilities. A survey of 37 ethnic community agencies and organizations serving Asian Americans was completed by 11 agencies. It was estimated that about 2,277 Asian Americans in the Chicago area might have mental retardation, but the number reported as being served was dramatically smaller, at about 117. Mainstream service agencies were more likely to serve more disabled and younger clients. Language-appropriate and culturally sensitive services are clearly needed for this population, and outreach and information dissemination activities are necessities if Asian Americans with developmental disabilities are to receive needed services. Seven appendixes contain surveys, forms, and letters. (Contains 5 tables and 20 references.) (SLD)

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A Study of the Special Needs of Asian Americans with Developmental Disabilities in the Chicago Metropolitan Area

A Project Commissioned by the:

Illinois Planning Council on Developmental Disabilities

Research Report prepared by:

Asian Human Services of Chicago, Inc.

June 1996

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A Study of the Special Needs of Asian Americans with Developmental Disabilities in the Chicago Metropolitan Area

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Established in 1978, Asian Human Services is a pan-Asian direct service community agency, providing a variety of multilingual programs and services to economically disadvantaged Asian American immigrants and refugees.

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FOREWORD

After this needs assessment study was initiated in May 1995, we made efforts through Asian ethnic agencies, the ethnic press, churches, temples and mosques to reach the nearly 300,000 strong Asian American population in the Chicago metropolitan area, to identify persons in their communities with developmental disabilities. The local mosque referred one immigrant family from the Indian subcontinent, who had lived in Chicago for ten years with their two developmentally disabled sons, aged 19 and 21. The young men stayed at home, did not go to school, and received no support services at all. The parent's looked after their sons all by themselves, believing their children's condition to be the will of God. They came to Asian Human Services for advise and help, and now both the sons are in a vocational rehabilitation program.

The case of the Ahmed family is typical of economically disadvantaged Asian immigrants and refugees who are reluctant to use mainstream social service delivery systems. The reasons for this are complex. Asians typically hesitate to seek help for problems relating to mental health or developmental disabilities. Concepts of shame, stigma, and traditional beliefs in keeping personal matters within the family play a role in keeping problems hidden. Most importantly, language barriers and lack of culturally appropriate information also inhibit Asian immigrants and refugees from accessing mainstream services.

These barriers are compounded further because mainstream social service agencies often make only token efforts to reach culturally and linguistically isolated ethnic communities. For example, based on conservative prevalence estimates, nearly 3,000 Asian Americans living in the Chicago area suffer from developmental disabilities such as mental retardation, cerebral palsy, and autism. However, in our survey of 112 agencies providing services to clients with developmental disabilities, Asian clients totaled *fewer than 100*. Clearly efforts must be made within the service delivery system to address this staggering discrepancy. We believe this needs assessment study, the first study of developmental disabilities among Asian Americans in Chicago, represents a first step to increasing support services to this special, and until now, "invisible" population.

Asian Human Services acknowledges a debt of gratitude to a number of people who contributed to this study. Rene Christensen Leininger, Director of the Illinois Planning Council on Developmental Disabilities, showed great courage and foresight in recognizing the need for research on developmental disabilities within Chicago's pan-Asian community. Malia Arnett, a member of the Council staff, provided invaluable support and direction. Dr. Martha Ellen Wynne of Loyola University generously gave her time, technical expertise and insight. Most of all, this study is the result of the tireless efforts of Keum-Hyeong Choi of Asian Human Services, who put in many long hours collecting and sorting data, conducting surveys, and writing the final report. I thank them all for their commitment and support.

Abha Pandya
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July 27, 1996

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I. Introduction and the Statement of the Issue

Individuals with developmental disabilities constitute a minority population in this country, and Asian-Americans with developmental disabilities are a minority client population within the service delivery system. The perceived image of Asian-Americans with developmental disabilities as a "silent minority" (Chan, 1981) has maintained the "invisibility" of this population in the public's mind and their special needs have been neglected, partially due to their families' own inability to articulate their positions.

The problems encountered by Asian-Americans with developmental disabilities are distinctive in comparison to the majority population with developmental disabilities in the U.S. due to their special needs stemming from their diverse cultural/linguistic backgrounds and living conditions. According to the 1990 census, over 7,200,000 Asian-Americans lived in the U.S., which comprises 2.9% of the total population. Asian-Americans are composed of at least 29 distinct ethnic subgroups that differ in culture, language, religion, values, lifestyles, and history. Very little is known about the current status of Asian-American people with developmental disabilities.

The present study aims to understand the special needs of Asian-Americans with developmental disabilities living in the Chicago area of Illinois. This goal is achieved through investigating multi-facets of service delivery for this population: 1) Prevalence rates and patterns of developmental disabilities among Asian-Americans in the Chicago area; 2) Service utilization status and patterns in mainstream and community service delivery systems; 3) Difficulties experienced by both service providers and Asian-Americans with developmental disabilities when they work together; 4) Barriers to effective service provision and utilization reported by service providers and the families of Asian-Americans with developmental disabilities; 5) Recommendations suggested by mainstream and community service providers and Asian-Americans affected by developmental disabilities.

The findings resulting from the present study will help the existing mainstream and community service delivery systems meet the unique needs of Asian-Americans with developmental disabilities by providing culturally effective services. Within the Asian-American communities as well, outreach and advocacy activities will be formulated to increase the awareness of the special needs of this population and to strengthen formal and informal network systems.

In general, the present study assumes that while distinct ethnic subcultures certainly exist within the Asian-American community, the common aspects of Asian cultures, when compared to mainstream cultures, are sufficient to provide a general understanding of the needs of Asian-Americans with developmental disabilities. In addition, the study also emphasizes the importance of recognizing the heterogeneity of Asian-American ethnic groups as well as individual differences. Further, while recognizing the variability among Asian-Americans due to between-group and individual differences, this study focuses on the Asian-American population that is relatively new to this country with limited English proficiency and in the middle to low

socioeconomic class. Therefore, any generalization or application of the findings of this study should take these limitations into account.

II. Current Status of Asian-Americans with Developmental Disabilities

In this section, the status of Asian-Americans with developmental disabilities is based on the current literature. Attempts have been made to estimate the prevalence of developmental disabilities among Asian-Americans. While there is a dearth of studies on Asian-Americans with developmental disabilities, other related disciplines repeatedly report that Asian-Americans tend to underutilize formal resources and to be underserved by the service delivery system. After the underutilization patterns are presented, the possible explanations for the underuse of social services by this population are explored. More specifically, barriers that might discourage families of Asian-Americans with developmental disabilities from seeking formal resources are presented at two dimensions: the unique characteristics of Asian-Americans with developmental disabilities as service consumers and the unresponsiveness of service delivery system as service providers. Finally, the need for deeper inquiry into the complex issues involved in the service delivery for this population is discussed.

Prevalence of Developmental Disabilities in the Asian-American Population

As noted, little has been written on Asian-Americans with developmental disabilities and no statistics on this population are currently available. Because of the absence of data, it is impossible to measure identifiable prevalence as well as true prevalence of developmental disabilities among this population from the current literature. In general, the President's Committee on Mental Retardation estimates that approximately 3% of the general population has mental retardation. While the validity of the often-cited figure of 3 % prevalence has been seriously challenged, most professionals in the field appear to believe prevalence rates to be less than 1% (Beirne-Smith, Patton, & Ittenbach, 1994). The 1% prevalence estimation might give a glimpse of estimated prevalence rates of mental retardation among Asian-Americans. Given the 1990 national census, the calculation of 1 % estimated prevalence rates of Asian-Americans with mental retardation yields the following information:

	Number of Total Asian-American Populations	Estimated Number of Asian-Americans with Mental Retardation
In the U.S.	7,273,662	72,736
In Illinois	285,311	2,853
In the Chicago Area	227,742	2,277

These numbers reflect only those of Asian-Americans with mental retardation and the prevalence rates would increase if the numbers of Asian-Americans with other types of developmental disabilities were added.

While the estimates of incidence and prevalence of developmental disabilities are influenced by definition of these disabilities, methodological techniques of identification, and sociopolitical factors, reviewers of demographic data have historically reported a disproportionate number of ethnic minority children being labeled as mildly mentally retarded. For instance,

national figures collected in 1987 on the racial and ethnic characteristics of secondary school youth with developmental disabilities and reported in the Fourteenth Annual Report to Congress (U.S. Department of Education, 1992) provide evidence that the disproportionate rate continues to exist. African-American youth are over two and one-half times more likely to be identified as mentally retarded than would be expected based on the population size. Interestingly, Caucasian students are under-identified and Hispanic students are much less likely to be identified as mentally retarded than expected. Polloway, Epstein, Patton, Cullin, and Luebke (1986) reviewed information on elementary and secondary students labeled Educable Mentally Retarded (EMR) who were receiving services in several medium-sized cities in northern Illinois. They also found a disproportionate number of ethnic minority students in EMR programs.

However, none of these and past studies on developmental disabilities reveal any clear information about Asian-Americans specifically as an ethnic minority group. They were either not categorized into one of the major racial/ethnic minorities (i.e., Caucasian, African-American, and Hispanic) or vaguely included in the category of "other" ethnicity. Thus, no further descriptive information is available on the prevalence rates of developmental disabilities in this population in terms of their ethnicity, gender, age, type of disability, severity of disability, and so on. In addition, the demographic and socioeconomic information about Asian-American families affected by these disabilities are not available at this time.

Utilization of Social Services by Asian-Americans with Developmental Disabilities

Very little information is available on the status of Asian-Americans' utilization of formal resources for developmental disabilities. It has been well documented that the ethnic minorities in this country, Asian-Americans, in particular, underutilize mental health services in the mainstream service delivery system. Plausibly, insofar as Asian-Americans make less use of health and mental health resources in the U.S., there is a strong possibility that Asian-Americans with developmental disabilities make less use of formal services available to them. Investigating Asian-Americans' utilization patterns of various social services is critical to understanding their underutilization status and possible reasons why this population is less likely to utilize formal resources they are entitled to and is underserved by the service delivery system.

In contrast to Caucasian clients, ethnic minorities in general repeatedly have demonstrated a pattern of limited use and premature termination in the mainstream service delivery system. For instance, Sue (1977) studied nearly 14,000 clients in 17 Community Mental Health Center (CMHCs) in the Seattle-King county areas during the years, 1971-1973, and found that African-Americans and Native Americans were overrepresented in the centers, whereas Asian-Americans and Hispanics were underrepresented. Regardless of underutilization rates, about half of the ethnic minority clients (52%) failed to return for treatment after one session, compared to the 30% dropout rate of Caucasians.

Among all the ethnic minority groups, Asian-Americans have been consistently reported as the group that least utilizes mental health services. O'Sullivan, Peterson, Cox, and Kirkeby (1989) followed up after 10 years the above cited work by Sue (1977) on the 13,789 clients seen

in 1983 in 20 CMHCs in the same areas. While the average number of sessions dramatically increased for all ethnic groups, the Asian-American group had the lowest mean number of sessions (11.5), and they were also the only ethnic minority group to have significantly fewer contacts with the CMHCs than the Caucasians (15.3). The review by Cheung and Snowden (1990) on national trends in minority utilization of mental health services also reported the similar results. In their study, utilization trends in the federally funded CMHCs in 1983 showed that for all types of services, Asian-Americans demonstrated the lowest rates of utilization relative to their proportion of the population (1.5%); inpatient care (0.4%), residential treatment (0.6%), residential support (0.6%), outpatient care (0.6%), and partial care (0.6%).

Possible Explanations for the Underutilization of Mental Health and Social Services

To account for the underutilization of mental health and social services by Asian-Americans, numerous possible explanations have been generated. One stereotypic reason involved the viewpoint that Asian-Americans are a "model minority," the one group to have successfully integrated into American society due to their strong work ethic and ability to take advantage of educational opportunities. Thus, lower utilization rates for health, mental health, and social services among Asian-Americans have led some to conclude that Asian-Americans have fewer mental or physical health problems (Crystal, 1989). However, the myths associated with Asian-Americans being the model minority could be erroneous due to the large within-group variability in educational achievement and socio-economic status found within a given Asian-American ethnic group, as well as large between-group variability within the whole Asian-American population. Moreover, this stereotype could be damaging because the institutional barriers and obstacles faced by this population could be overlooked.

More plausible explanations for the low utilization by Asian-Americans appear to be found in the characteristics of the two parties involved in the service delivery to this population: a) Asian-Americans as service consumers and b) the mainstream service delivery system as service providers. The former source of explanations involves some socio-cultural characteristics common to Asian-Americans which might lead to the underutilization of outside professional services: their cultural perceptions of mental disturbance such as shame and stigma associated with mental illness (Flaskerud, 1986; Sue & Sue, 1990) and their cultural styles of help-seeking behavior of using alternative resources to solve their personal problems (e.g. family, family physicians, traditional healers, clergy, and the churches) (Lin, 1983).

The second source of explanations involves the mainstream service delivery system (Sue & Sue, 1990). Over a few decades, American psychology and the mental health disciplines have engaged in a great deal of self-criticism over the sensitivity of mental health services to ethnic minority groups. The criticism has focused on incompatibility or unavailability of services, therapist's lack of knowledge and understanding of socio-cultural contexts of ethnic minority clients, prejudicial and discriminatory practices, and so on (Sue & Sue, 1990; Sue & Zane, 1987). With regard to unresponsiveness and inaccessibility of services, in many instances at the system level, service facilities are not located in the client community, and there is little effort to publicize services and make them known to community clients (Sue, 1977). In addition, there is a serious

shortage of ethnic therapists to meet the demands of ethnic populations (Casas, 1985). This shortage is particularly acute for clients who want or need bilingual/bicultural therapists (Sue, 1988). Some investigators, however, argued that the single most important reason for the problem is the inability of therapists to provide culturally relevant or responsive forms of treatment (Flaskerud, 1986; Sue, 1988; Sue & Zane, 1987). Their assumption is that most therapists are not familiar with the cultural backgrounds and life-styles of the client and have received training primarily developed for Caucasian, or mainstream Americans (Sue & Sue, 1990). Consequently, therapists are often unable to devise culturally appropriate forms and modalities of treatment, and ethnic minority clients frequently find mental health services strange, foreign, or unhelpful (Sue & Zane, 1987).

Barriers to Effectively Utilizing Formal Services for Asian-Americans with Developmental Disabilities

There is a paucity of studies in the literature which identify the reasons why Asian-Americans with developmental disabilities as a client population group might not utilize formal resources and services available to them and might be consequently underserved by the service delivery system. A few studies addressed the difficulties that Asian-Americans with developmental disabilities and their families might experience in the process of accessing to the mainstream service delivery system and of interacting with mainstream service providers. Barriers causing underutilization of formal services can be understood as multiple interactive factors between the characteristics of Asian-Americans with developmental disabilities and of the mainstream service delivery system for people with developmental disabilities.

A. Characteristics of Asian-Americans with Developmental Disabilities and Their families

Language Barriers and Lack of Language- & Culture-Appropriate Information

One of the major barriers to service is the fact that many Asian-American families and individuals with developmental disabilities speak their native languages that are different from the service providers'. Communication difficulties and the lack of language-appropriate information concerning the nature of disabilities and the course of interventive actions seem to discourage Asian-American families from actively seeking formal resources throughout the diagnosis and treatment processes. The lack of understanding and subsequent confusion due to the lack of knowledge of the health care and educational systems in the U.S. appear to be other significant barriers. Although some of the same confusion and lack of understanding exists for Caucasian counterparts, language differences present significant additional burdens for Asian-American people with developmental disabilities and their families.

After interviewing a sample of 59 Chinese American families of children with developmental disabilities in New York, Smith & Ryan (1987) and Ryan & Smith (1989) reported some of these parents' reactions to the processes of diagnosis and treatment for their children. This group of parents were receiving medical services and involved in a school program or a sheltered workshops. These parents were utilizing diagnostic services (56%), speech therapy (42%), and

transportation (42%) more often than services such as counseling (27%) and physical therapy (20%). The following are some of the important thematic issues emerging from each stage in the service delivery process.

At Initial Diagnosis: The biggest problem caused by the language and communication difficulties seemed to be simply "not knowing what is going on." Most of the physicians, nurses and social workers involved did not speak Chinese and reportedly were inept at explaining medical terms unfamiliar to these parents. As the result of the confusion created by the lack of understanding of the medical and educational systems, the child's diagnosis seemed to be delayed. Over two-thirds of the parents in the study learned about their child's disability after the child had become one year of age. Due partly to the lack of awareness of the disability, it often took a long time for these parents to obtain a diagnosis and seek significant help.

Parents were apt to have better understanding of the formal diagnosis of mental retardation, cerebral palsy, and epilepsy, but they had difficulty in understanding cases of neurological impairment, autism, and learning disabilities. Common reactions of these parents to the initial diagnosis were denial, guilt, and partial acceptance of their child's condition. The parent's lack of understanding also seems to contribute to tending to perceive the disability as a temporary problem. What these parents needed most seem to be basic, intensive information about the nature of developmental disabilities and the health care and educational systems for people with developmental disabilities.

At the Access to Services and Service use: After diagnosis, confusion and lack of understanding appear to restrict which programs these parents might have access to and whether they would pursue services. The parents felt "inconvenienced," "embarrassed," "frustrated," and "scared" due to the communication difficulty between the service providers and them. Language difficulties consequently appeared to affect their access to the services and use of the services, and limit the usefulness of the services.

As a way of overcoming language barriers due to the lack of bilingual professionals among provider agencies, translation services were often sought at the time of diagnosis and later phases of treatment. However, translators often seemed to be unavailable to these parents in case of need and emergency. When these formal translation services were not available, these parents turn to a family, a relative, a friend, or a neighbor. These informal translators, however, are at times very unreliable and inconvenient. Even formal translation services brought some confusion and uncertainty due to the translators' own lack of understanding of specialized medical terms and diagnostic concepts. Parents appeared to prefer speaking directly to professionals in their own language or utilizing translation services provided by a reliable and competent bilingual case manager or service provider who is familiar with the specialized terminology.

Socio-cultural Factors

Understanding of socio-cultural characteristics of Asian-Americans with developmental disabilities responsible for the underutilization of formal services would help uncover barriers to their access

to the service. Understanding how Asian-Americans perceive both the etiology of the disability and issues related to the diagnosis and treatment of individuals with developmental disabilities might shed some light onto their thinking and decision-making processes in the care of their family member with a developmental disability. Their socio-cultural perceptions not only encompass different views on the cause of mental and physical disability but also different attitudes and behaviors associated with seeking help than in mainstream families.

Traditional Beliefs of the Causes of Disability/Disease: The Asian traditional beliefs and value systems dictating the perceptions of the cause of disability or disease can determine Asian-Americans' response to people with developmental disabilities and the subsequent course of treatment sought. Chan (1976) described some of the traditional perceptions shared by the Chinese of a person with a disability:

> Many people perceived the cause of the disease as a heavenly retribution for the evil things committed by the afflicted person, his family, and/or his ancestors....People wonder what evil was committed, ignoring the person with the disability; thus further barriers are created in understanding the problem. Disability is seen as having its source in wrongdoing, and there is not much interest in remedial therapy....They believe one cannot have a sound mind unless one has a whole and sound body (p.16).

In the traditional Chinese society, mental illness and mental deficiency were viewed as evil, bringing shame to the family name. In addition, many Asians traditionally believed that people should live in harmony with their surroundings by maintaining self-control and restraining strong feelings. Thus, rather than bringing individuals with a mental disability to the attention of professionals for help, family members tended to hide them or handle the problem on their own terms (Sue & McKinney, 1975). It is unclear how many of these Asian traditional beliefs are still held by Asian-Americans in the U.S. More studies are needed to determine how service utilization patterns differ as a result of these perceived causal attributions of the disability.

Specifically, Ryan and Smith (1989) described three causal determinants of disability or disease which are perceived by many Asian ethnic groups:

> Chinese-American families may consider physical agents, supernatural agents and/or metaphysical elements to explain why the child is developmentally disabled: a) Physical agents are "natural" factors and elements which impinge in the body by infraction or bring about harmful changes...; b) Supernatural causes are less often considered today, as people are more conversant with the natural sciences; however, they still lurk in the back of many minds when symptoms are obscure and incomprehensible and no single direct causal explanation is evident and available, such as in most developmental disabilities. The origin of disease then, is ascribed to the action of supernatural powers intervening after a fault, a violation of religious or ethical codes, or simply an accident which caused displeasure to some deity who angrily struck the poor soul....; c) Metaphysical causes are a third causal determinant of disease. Traditional Chinese medicine is based upon a belief in metaphysical causes derived from the central concept of Chinese cosmology.

> The human body operates with a delicate balance between two basic forces, Yin and Yang, and this balance is essential for good health. An excess in either direction leading to disequilibrium, meaning a deranged physiology, discomfort, and illness. Because of its heat, excessive Yang causes fever; because of its coldness, excessive Yin produces chills. The golden rule in medicine, which consists of juggling the hot (Yang) and cold (Yin) qualities of drugs, food and other natural elements to fit the hot and cold status of the body organs so that one may retain or regain the vital balance. This hot-cold dichotomy exists in the context of food and food habits that promote health rather than in the context of medicine per se (pp. 292-294).

In the interview study with 59 Chinese-American parents with children having developmental disabilities, Ryan and Smith reported that fifteen percent of the parents in the study believed that outer physical elements such as "the birth control pills," "the long labor," or "dredging the mud and sand too often during pregnancy" had caused their child's disability. Ten parents in the study attributed the cause of their child's disability to the mystical "fates" (e.g., "It is my fate to have such a child"; "The Gods looked unfavorably on me and sent me bad fortune"; "Maybe it is my fate, because I had to fix the doors during pregnancy"). In the context of the metaphysical causes of Yin and Yang, several parents attributed the cause of their child's developmental disability to the "colds and fevers" or frequent "high fevers" that their child suffered in infancy or during earliest childhood.

Culture-Specific Modes of Treatment: The aforementioned traditional beliefs in the importance of physical, supernatural, and metaphysical causes might suggest that Asian-Americans' basic orientation to a developmental disability often conflicts with the Western causal and diagnostic systems for developmental disabilities and lead them to seek some culture-specific traditional cures instead of seeking the mainstream services. For instance, some Chinese-American parents in the Ryan and Smith (1989)'s study reported, the use of acupuncture, in conjunction with the Western medical treatment, taking the child with a developmental disability to the mediums of Chinese Gods to offer incense to drive away the evil spirit, which they believed took possession of. They sought supernatural cures not only for relief of symptoms, but also for release of some of their own anxieties, fears, and guilt feelings.

Familial Style and Cultural Modes of Handling Disability: Culturally unique familial interactions and expectations for the members' duty and role in family might determine the way of taking care of a family member with a disability. In some traditional Asian cultures where there is the Confucian tradition, people would feel obligated to take care of their elderly, their children, and people with disabilities. Filial piety and familial responsibilities were the determinants of their way of life and demanded social, economic, and emotional support to one's nuclear and extended family throughout one's life. In many Asian societies, there are few institutions for elderly people or people with mental and physical disabilities; therefore, each family in order to save the family name from disgrace must take care of the less able members. And if they neglect their duty in taking care of the person with a disability, they can be criticized by the community. Only a small number of the families would consider placing their family member with a developmental disability in an institution (Chan, 1976).

In conclusion, both language barriers and socio-cultural factors embedded in the Asian-Americans' perceptions of causes of and treatment for developmental disabilities might shed some light on understanding the underutilization of formal resources. However, it is not still clear how much of the lack of understanding of the etiology and treatment of developmental disabilities is the result of language, and how much is based on socio-cultural differences in the perceptions of disabilities and help-seeking behaviors. The varying roles of language differences, socio-cultural factors, socioeconomic status, acculturation, and religion should also be examined, insofar as these factors contribute to the quality and quantity of use of formal resources by Asian-Americans.

B. Unresponsiveness of the Service Delivery System

Chan (1981), after the review of some studies investigating the significant underrepresentation of Asian-Americans among the client populations in California state agencies, reported the following reasons as primary barriers embedded in the service delivery system for Asian-Americans with developmental disabilities:

> *a)* Lack of information about available resources and institutional barriers are primary deterrents to effective utilization of existing services by Asian-American families. *b)* More specifically, many developmental service agencies have been characterized by inadequate community outreach and organization efforts within Asian-American communities; agencies have also remained inaccessible by way of their geographic isolation from target communities, limited hours of operation, and lack of bilingual staff or efficient interpreter services. Additional findings have revealed that, as consumers of specialized services for developmentally disabled family members, a significant number of Asian-American families demonstrate a general preference for same-ethnic service providers (p. 3).

In order to overcome these barriers, the development and implementation of more effective services and corresponding organizational activities have been initiated in Los Angeles County in California, approximately two decades ago. The following are summaries of their activities that served to increase the awareness of the special needs of Asian-Americans with developmental disabilities:

1. Augmentation of Existing Services

-- The establishment of direct contact and communication with specialized ethnic social service agencies located within the Asian-American communities
-- Information dissemination and systematic outreach efforts aimed toward specific health care agencies, ethnic physicians practicing within selected communities, major community institutions (e.g., schools, churches), various ethnic community organizations, and existing indigenous community care and support systems.

--The employment of bilingual-bicultural Asian-American staff as intake workers, client program coordinators, professional consultants, and community liaison specialists.

-- Results: 1) the development of an information and referral network characterized by more immediate access to selected Asian-American populations, and 2) corresponding significant increase in Asian-American client referrals.

2. Specialized Ethnic Services

-- The establishment of specialized programs which are based in Asian-American communities and are staffed by fully bilingual-bicultural professionals: One such program, the Asian Rehabilitation Services (ARS) Outreach Unit, was established in 1976. The ARS Outreach Unit was designed to provide specialized services to non-English speaking Asian-Americans with developmental disabilities and their families residing within Los Angeles County. The Unit consisted of bilingual Chinese, Japanese, Korean, Filipino, and Vietnamese staff who engaged in activities consistent with the following objectives: (1) community outreach and identification of Asian-Americans with developmental disabilities in need of specialized services; (2) community education regarding the needs of Asian-Americans with developmental disabilities and corresponding resource development; (3) the provision of linkages between developmentally disabled Asian-Americans with developmental disabilities and service providers. Given its target population, program objectives, and multi-lingual capabilities, the ARS Outreach Unit was the first of its kind in the nation.

-- Significant Advocacy: In testimony at the Civil Rights Hearings sponsored by the California State Department of Health in November 1976, ARS staff presented documentation of numerous problems within existing service delivery systems for Asian-Americans with developmental disabilities. These problems included a lack of bilingual staff and culturally relevant assessment methods, cultural insensitivity, and failure to deliver readily available services to Asian-American communities. Continued ARS advocacy activities, including a series of meetings with various State Department heads and program administrators, ultimately resulted in supportive efforts to systematically improve services to Asian-Americans. ARS was officially designated in 1977 as a contract agency for the Regional Centers serving Los Angeles County: Through interagency agreement, the ARS Outreach Unit provided intake, case management, and translation services for Asian-American clients registered with various Regional Centers. Additional program development has been characterized by greater coordination of developmental, educational, health care, mental health, and social services provided by specialized service agencies and training programs.

Results: Collaborative client-focused as well as program development activities among the agencies: centralized referral systems, comprehensive coordinated multi-service networks, and mechanisms to assure continuity of services among existing agencies.

3. Local and Regional Organizations

-- Corresponding organizational growth and development in existing agencies and specialized community-based services: Within the developmental disabilities field, the progressively increasing number of Asian-American service providers and consumer advocates has fostered the formation of organizations such as Asian-American Rehabilitation Services and the Committee on Asians with Developmental Disabilities (CADD). CADD is particularly unique in that it was one of the first organizations to specifically address the needs of Asians with developmental disabilities in the East Bay area. Since the inception of CADD in 1977, its membership has grown to include representatives from a variety of programs. By means of advocacy, education, and consultation, CADD continues to pursue its primary goal of insuring that generic and Asian-American service providers meet the needs of Asian-Americans with developmental disabilities.

-- The establishment of a much needed communication network among those who are directly concerned about Asian-Americans with developmental special needs: Within the past year, several individuals from areas throughout California and Hawaii have collaborated in the development of a Pacific Asian Network (PAN). PAN was designed to augment services for Asian-Americans with developmental disabilities by means of a regional information and referral systems. The system was based upon data gathered from Asian-Americans and other ethnic minorities involved in the administration, education, training, research, consultation, advocacy, and service delivery for the people with developmental disabilities. Information pertaining to specific individuals and resources was be coded and processed through computer facilities in a centralized location. The corresponding data bank or information clearing house could then be utilized by individuals, organizations, agencies, and institutions for numerous purposes: *a)* employment (job recruitment); *b)* identification of candidates for membership in various local, state, regional, and national boards, committees, task forces, etc.; *c)* community resource and program development (e.g., interagency collaboration, support with respect to developing grant proposals, new services or projects); *d)* training and technical assistance (e.g., identification of individuals available to participate in conferences, symposia, workshops as speakers or trainers for both Asian-American and non-Asian-American professionals, para-professionals, and consumer advocates; *e)* development of training models and educational materials for administrators, service providers, and consumers); delivery to client populations with distinct ethnic, age, clinical, and/or other characteristics); *g)* direct service (local and regional interagency communication, coordination of services to clients -- particularly those moving to new areas; *h)* identification of bilingual-bicultural service providers with specialized skills in a given professional discipline or area of expertise);*i)* information development and dissemination (publication and distribution of announcements, newsletters, articles, media, and other materials); *j)* general support and advocacy (developing strategies for unifying consumers and those concerned about the needs of Asian-Americans with developmental disabilities) (Chan, 1981, pp. 3-6).

Need for Research in the Study of Special Needs of Asian-Americans with Developmental Disabilities

The dearth of studies on Asian-Americans with developmental disabilities does not provide complete information about the current status of this population and it does not provide a full understanding of barriers to meeting their special needs. Even the findings obtained from a few studies with a single sample of a specific Asian-American ethnic group have limitations in their generalization due to the fact that the Asian-American population is comprised of heterogeneous groups with diverse ethno-cultural origins and languages. In addition, because of the complexity of the issues stemming from the double minority status of Asian-Americans with developmental disabilities, in terms of their ethnicity and disability conditions, corresponding research activities should take into account these special issues.

1. Need for Research in Prevalence of Developmental Disabilities among Diverse Asian-American Ethnic Groups

Most of all, due to the lack of current data on the status of Asian-Americans with developmental disabilities in this country, baseline data of prevalence and incidence of these disabilities in this population need to be established. Chan (1981) described the direction for these research activities:

> Clearly indicated is the need for continued *descriptive research* regarding the prevalence and distribution of developmental disabilities among various Asian-American populations, particularly in communities with high concentrations of Asian-American populations; *parallel research* efforts must be conducted to ensure that census and other demographic data for the general population accurately reflect current Asian population characteristics, including distinctions between the various Asian-American ethnic groups. Epidemiological studies and corresponding systematic casefinding activities would serve to both document and specify population needs (pp. 6-7).

2. Need for Research in Special Needs due to the Socio-cultural/Linguistic Characteristics

It is necessary to understand how socio-cultural factors involved in the perceptions of the etiology and the treatment of developmental disabilities affect Asian-Americans' utilization patterns of and special needs for services. The social, cultural, and linguistic contexts in which developmental disabilities are understood and handled by this population must be carefully studied. There is a need for research concerning characteristic family socialization including culture-specific familial role expectations, parent-child interaction styles, and child-rearing practices, found in diverse Asian-American ethnic groups. Additional consideration should be given to the impact of specific historical events, government policies, and socioeconomic conditions upon Asian-American families in America.

3. Need for Research in Culture/Language-appropriate Clinical and Social Service Programs

As much as the understanding of the etiology of developmental disabilities is different in Asian-American ethnic groups, medical concepts and terminology appear to be different across the diverse cultures, especially between Eastern and Western cultures. The medical diagnostic systems for developmental disabilities are different, especially in China where those of mental retardation or Down syndrome are well established, but the diagnosis of autism is not (Gorelick, 1981). In addition to investigating differential diagnostic systems across cultures, it is necessary to develop culturally relevant clinical assessment methodologies and explanatory systems for Asian-Americans affected by developmental disabilities. Research efforts should also be directed to the area of clinical assessment of psychological, social, and intellectual functioning in non-English speaking Asian-Americans with developmental disabilities.

4. Need for Research in Program Evaluation

The existing formal service programs within the mainstream service delivery system should be continuously evaluated to assess the relative effectiveness of present service programs for diverse ethnic populations. The results should be incorporated into the development of culturally sensitive interventions tailored to the needs of Asian-Americans with developmental disabilities.

III. Needs Assessment of Asian-Americans with Developmental Disabilities in the Chicago Area

In this section, a series of studies conducted for needs assessment of Asian-Americans with developmental disabilities living in the Chicago area is presented. The descriptions of the demographic characteristics and historical accounts of diverse Asian-American populations living in the Chicago area are presented to provide background information about Asian-Americans with developmental disabilities under study. The next section describes the methodologies used in the present study and its findings.

A. Background: Demographic and Historical Descriptions of Asian-Americans in the Chicago area

Asian-Americans are the fastest growing segment of the U.S. population today. Over the last three decades the Asian-American population has ballooned. The number of U.S. residents who originated from Asia and the Pacific Islands was 3,556,465 in 1980 and had more than doubled from a decade before. By 1990 the population increased another 95 percent to 7,273,662. The Asian-American population growth in Illinois mirrors the national pattern. In 1990 Illinois ranked fifth among the states in Asian-American population, with a total of 285,311.

Chicago and its six surrounding counties have the one of the largest concentrations of Asian-Americans in the United States metropolitan areas. However, unlike other Asian-American populations, Chicago is unusual for its large proportion of Asian Indians and Filipinos, who together account for nearly 50 percent of all Asian-Americans in metropolitan Chicago. The other half of the Asian-American population consists of persons of Chinese, Korean, Japanese, and Vietnamese, Laotian, Thai, and Pakistani descent.

The overwhelming majority of Asian-Americans in Illinois are concentrated in the Chicago area. According to the 1990 Census, 227,742 Asian-Americans live in the primary Chicago area (i.e., Cook and DuPage Counties) with only 45 percent of that number living in the city of Chicago. In the city of Chicago, Asian-Americans have clustered in the near south side (Chinatown/Armour square, Bridgeport) and the far north side (Uptown, Edgewater, Rogers Park, Lincoln Square, Albany Park, West Ridge, North Park, and Forest Glen). In the city of Chicago, Filipino (26.8%), Chinese (21.8%), Indian-Pakistani (16%), Korean (13.6%) population groups dominate, accounting together for 78.2% of the total Asian-American population in the city. There are smaller, but significant numbers of Japanese, Vietnamese, Cambodian, Thai, and Laotians in Chicago (See Table 1).

Table 1. *Asian-Americans in Chicago Primary Metropolitan Statistical Area (PMSA), 1990*

Ethnic Group	Chicago PMSA	Chicago city

Filipino	54,411	27,443
Asian Indian	53,702	16,386
Chinese	40,189	22,295
Korean	33,465	13,863
Japanese	17,310	6,696
Vietnamese	7,313	4,640
Thai	3,955	1,880
Cambodian	2,456	1,920
Laotian	1,781	.703
Hmong	212	102
Other Asian	12,948	7,010

With the exception of Chinese-Americans, Vietnamese-Americans, and Cambodian-Americans, more than half and sometimes as much as two thirds of all Asian-Americans live in suburban Chicago. The majority of Asian-Americans live in the suburbs, making them the only racial minority with that demographic characteristic. Asian-Americans have concentrated in North, Northwest and Western suburbs, often constituting the largest minority group in many suburban municipalities. Skokie is the suburb with the largest Asian-American population of 9,253, which amounts to 15 % of the overall population. Other suburbs having substantial Asian-American populations include Naperville, Schaumburg, Hoffman Estates, Evanston, Mount Prospect, Morton Grove and Downers Grove.

1. Chinese-Americans

Although Chinese men and women have lived in Chicago since the late nineteenth century, most of the over 40,000 Chinese living in metropolitan Chicago arrived in the United States after World War II. The repeal of the Immigration Exclusion Act (which had severely limited Chinese immigration between 1882 and 1943, the refugee resettlement acts after World War II, and family reunification programs led to a sharp increase in the Chinese population of Chicago. In the 1950s with the influx of refugees from the communist takeover of mainland China, the Chinese-American population doubled to 6,000. In the 1960s and 1970s the majority of Chinese immigrating to the Unites States were from Hong Kong, Taiwan, or the ethnic Chinese from Southeast Asia who fled at the end of the Vietnam War. However, when mainland China and the United States opened diplomatic relations in the 1970s, a number of Chinese from mainland China applied for visas.

Many of the new immigrants who came from mainland China in the 1980s through family reunification provisions of the immigration law have settled in Chinatown and the Bridgeport area of near South Chicago. These immigrants were occupationally diverse including professionals, students, blue-collar workers, as well as former farmers. After the Tiannamen Square massacre, many Chinese men and women on student visas have been allowed to stay in the United States. Although many of the nineteenth century immigrants and especially those more recent immigrants from Hong Kong are Cantonese speaking Chinese, the majority of recent immigrants both from mainland China and from Taiwan speak Mandarin Chinese.

The Southeast Asian Chinese, who immigrated originally from Fukien province in the coastal area of China many centuries ago, speak both Cantonese and Mandarin. Many of the Southeast Asian Chinese initially settled in the Uptown area of Chicago, where a sizable Chinese community had already been established in the 1960s and 1970s. Many of the Southeast Asian Chinese had formerly been businessman and quickly established retail businesses and restaurants in Uptown and on the far north side of Chicago once they settled. The Southeast Asian Chinese community has developed its own social and political organizations because their history and needs were different from the direct immigrants from mainland China and Taiwan.

Chinese in Chicago draw on a variety of spiritual traditions. Many practice a mixture of Buddhism, Taoism, animism and Confucian philosophy and worship at private shrines and alters at home. There are no separate Buddhist or other religious temples for the Chinese as there are for the Japanese and Southeast Asian communities. However, Chinese people who have adopted Christianity have established a number of institutions including churches and schools. One of the most prominent of these is the Chinese Christian Union Church on Wentworth Avenue, in China town. In addition to numerous Protestant churches, there are also several Catholic Chinese institutions. The Chinese in Chicago also draw upon a variety of indigenous medical therapies such as acupuncture/acupressure and herbal medicine. For cultural communication and entertainment, there are four Chinese language daily newspaper available in Chicago. These dailies are circulated among Chinese communities throughout the United States. There is also a Mandarin-speaking television program established in 1983 and a local radio station, Global Communication, established in 1989.

Today, Chinese constitute the third largest Asian minority group in the greater Chicago area. According to the 1990 census, more than half of all Chinese in the Chicago metropolitan area live in the city of Chicago (22,295), concentrated in the near South Side or the far north side of the city. Since the 1960s, growing numbers of Chinese have moved to the suburbs. Increasing numbers of Chinese have moved to the Northwest suburbs and there are large concentrations of Chinese in the suburbs of Evanston (1,014), Skokie (1,334) and Naperville (1,456) and also in the Lake County (1,941).

2. Japanese-Americans

Japanese-Americans in metropolitan Chicago, according to the 1990 Census, number 17,310, approximately 7.6% of the total Asian-American population. Today's Japanese-American population in Chicago has its roots in the internment of Japanese-Americans during World War II. There was a small Japanese-American population in Chicago prior to World War II. In 1942 Japanese-Americans suffered unprecedented persecution by the U.S. government, which forced all people of Japanese ancestry on the Pacific Coast to move. More than 111,000 of the 126,000 Japanese in the United States were affected by this order. Within a year, it became clear that there were no grounds for fear of Japanese-Americans as a threat to national security, and the U.S. government began slowly to move Japanese residents to the East and Midwest. From 1943 to 1950 nearly 30,000 Japanese-Americans migrated to Chicago. Many stayed in the city

permanently, but almost half returned to the West Coast region when the emergency regulations were lifted. The Japanese-Americans who had previously lived as farmers and small businessman began to work in various light manufacturing and service occupations in Chicago, such as clothing, printing, furniture and cabinet factories as well as service trades in hotels and restaurants. Many Japanese-Americans were able to settle on the north side and the Hyde Park-Kenwood neighborhoods.

Japanese-Americans belong to a range of social, political, and religious organizations. In addition to the Japanese-American Service Agency (a social service agency) and the Japanese American Citizen's League (advocacy group which was instrumental in the national struggle for government apology and redress for the victims of internment), Japanese-Americans support Buddhist Temples and Christian Churches in the northern suburbs.

Increasingly, younger Japanese have been able to use higher education to achieve professional and managerial positions and establish themselves in the middle class. Since the 1960s, Japan's corporations have established offices in Chicago which now number 300. It is estimated that Japanese nationals and their dependents number to more than 3,500, or more than 20 percent of the total Japanese population in Chicago. Japanese-Americans who have lived in the United States for several generations are much more fluent in English than in Japanese. However, the newer Japanese nationals who live in the United States temporarily may have more difficulty with English. Although Japan's primary and secondary schools provide instruction in English, most Japanese have greater facility in reading English than in speaking it. During the last fifteen years, Japanese-Americans have moved in large numbers to the suburbs. More than 60% of the Japanese-American population in metropolitan Chicago live in the suburbs, particularly the northern suburbs with significant numbers in Arlington Heights (852), Schaumburg (948), Skokie (518) and Elk Grove Village (580) and also Lake County (1,108).

3. Filipino-Americans

According to the 1990 Census, Filipinos are the largest Asian-American group in the Chicago metropolitan area. The Filipino population of 54,411 is split evenly between the city of Chicago (27,443) and its suburbs. Nationally, over three-fourths of the Filipino population were born in the Philippines. Since 1965 many of the immigrants have been professionally trained in fields such as nursing, medicine, engineering, accounting, and pharmacy. Most left the Philippines because of high unemployment and low wages. The search for better opportunities in the United States has frequently been ambivalent; many Filipino women and men who have been trained in professional and technical occupations in the Philippines work as clerks, salespeople, and wage laborers in the United States.

Many of the more recent Filipino immigrants are from Manila and other urban centers, have received higher education and are familiar with American popular culture and American slang. Many speak their native Tagalog and Spanish. Filipino residents in Chicago in the middle of the twentieth century were from rural backgrounds and were mainly laborers who worked as migrant agricultural workers, in food processing industries, as manual laborers and blue collar

workers as well as a small population of students and professionals. Many of this earlier wave of Filipino immigrant men married European and Mexican women in Chicago and raised intercultural families tied together by Catholic churches and social organizations. Recent immigrants come more often as families and continue to be active in the Catholic parishes.

Filipinos are dispersed throughout the north and west section of Chicago and also live in the western, northwestern and northern suburbs. A substantial number of Filipinos live in the suburbs of Skokie (2,416), Niles (415), Hoffman Estates (562), Elk Grove Village (416), Cicero (517), Hanover Park (454), Downers Grove (504) and Bolingbrook (883). There are also large numbers of Filipino residents in the collar counties such as Lake County (4,053) and Joliet (1,433).

4. Asian Indian-Americans

According to the U.S. Census, there are 57,992 Asian Indians in Chicago and its six surrounding counties and they account for fully 25 percent of all Asian-Americans in the area. Most Asian Indians (53,702) live in the primary metropolitan area of Chicago (Cook and DuPage counties). Very often other South Asians, namely Pakistanis, Sri Lankans, and Bangladeshis are lumped together with Indians. The U.S. Census, however, enumerates Asian Indians separately from other South Asians. In Chicago, there are frequent references to the "Indo-Pak" community, and this requires clarification regarding the numerical strength of each community. There are 64,200 Indians in Illinois, compared to 9,085 Pakistanis, 311 Sri Lankans, 263 Bangladeshis.

The population of Asian Indians in the United States remained small, hovering from 2,000 - 5,000 from 1910 to 1965. Most were agricultural workers in California and a handful of university students and professionals. The 1965 revision of the Immigration law which abolished the stringent national origin quotas, provided for family reunification and granted visas for specialty skills and talents in high demand in the United States made it possible for large numbers of Asian Indians to immigrate, primarily as university students and professionals in engineering, physics, physical sciences and medicine. The transition to U.S. higher education and professional culture was eased by the familiarity of Indian immigrants with the English language, a legacy of British colonialism.

The financial success of the first wave of Indian professional immigrants drew subsequent waves of family members who were nonprofessional and other Indians from India, as well as those who had earlier immigrated to Kenya, Uganda, Tanzania, United Kingdom, Fiji and Trinidad before coming to the United States. These more recent waves of immigrants started business, sought blue-collar and service employment. In the city of Chicago, Asian Indian and Pakistani taxi drivers and convenience stores are as common as Indian physicians. Newer immigrants have less access to higher education and are far less comfortable with the English language. The stark economic and professional differences in the Indian community are mediated by family ties and ethnic bonds, but it is being increasingly recognized that the Indian community is diverse in its characteristics and needs.

There are also significant linguistic, ethnic and religious differences. Although Hindi is the national language of India, most people prefer to speak one of fourteen regional languages recognized by the Indian government and taught in schools in India. In a survey of the Chicago Indian community, it was found that 30% speak Gujarati, 18% speak Hindi, 9% speak Punjabi, 8% speak Telegu, 8% speak Malayalam, 6% speak Tamil, 5% speak Kannada, and 4% speak Bengali. It should be noted that Pakistanis speak Urdu, Sindhi and Punjabi and Bangladeshis speak Bengali. These languages are not only a medium of communication but they draw distinctions in culture, cuisine, art, literature and in immigrant communities, function as a marker of ethnicity. The relationship between regional linguistic identities and religious affiliations is no less complicated. For instance, Gujaratis can be Hindus, Jains, Muslims, Christians or Zoroastrians. The dominant religion for Indians is Hinduism (for Pakistanis it is Islam). In a Chicago survey, 80% of Indian respondents identified themselves as Hindu, 7% Christian, 5% Muslim, 4% Sikh, 3% Jain and 1% Zoroastrian. The major religious institutions are in the suburbs and in the north side of Chicago. They included Gita Mandal of Chicago, Hindu Temple of Lemont, Balaji Temple of Aurora, Swami Narayan Temple of Wheeling, Masjid A Noor of Chicago, Islamic Center of Naperville, Jain Temple of Bartlett, Sikh Gurudwara of Palatine and the Zoroastrian Association of Hinsdale. Indian television such as *Chitrahaar* and radio programming (Indian/Pakistani hours) in Chicago is dominated by music/dance sequences from Hindi films and other forms of musical entertainment. The print media in the region includes two English-language community newspapers: *Indian Tribune* and *India Spotlight*.

During the 1970s and early 1980s, Asian Indians concentrated on the north side of Chicago, particularly in Edgewater, Rogers Park, Lincoln Square, West Ridge, North Park and Albany Park. Many from that first wave have moved to the northern, northwest, and western suburbs. Newer immigrants often, however, prefer to live in the north side city neighborhoods close to ethnic shopping on Devon Avenue. Many other relatively new immigrants go directly to the suburbs where their families and friends have already made their homes.

This has resulted in a distinctive pattern of immigrant suburban settlement. While the city of Chicago experienced a 46% growth rate in its Indian population between 1980 and 1990, the suburbs saw a far more dramatic rise of 102 %. Asian Indians live in significant numbers in Evanston (632), Skokie (2,292), Schaumburg (1,218), Naperville (1,468), Niles (557), Hoffman Estates (1,347), Hanover Park (964), Mount Prospect (1,291), Des Plaines (1,051), Downers Grove (698) and Bolingbrook (566). In addition, Asian Indians are dispersed in the Chicago collar counties, including Joliet (1,286), Aurora/Elgin (808), and Lake County (2,257).

5. Korean-Americans

Koreans number approximately 36,000 in Chicago and its six collar counties, constituting approximately 15% of the overall Asian-American population. The first Koreans in Chicago were students and workers in the early twentieth century. After the Korean War, there were increasing numbers of students and war brides, who were generally ostracized by the Korean male students for having married outside their ethnic group. The 1965 Immigration Act resulted not only in rapid increases of the Korean population in Chicago but also transformed the population from a

temporary student population to a permanent immigrant population when waves of Korean miners and nurses began to arrive in Chicago from West Germany. Beginning in 1963 the South Korean government had contracted with West Germany to employ Korean miners and nurses as temporary "guest workers." When West Germany began to expel these workers in the 1970s, many went to the United States. Many of the female nurses found immediate employment in Chicago hospitals, while the miners turned to higher education and businesses. In the last two decades, an increasing number of immigrants come from Korea directly.

With the sharp increase in immigration, many new churches have formed. In 1984 there were 95 Protestant churches, one Catholic church, and four Buddhist Temples. By 1991 the number of Protestant churches had grown to 150 and two more Catholic churches were formed. The majority of churches are not free-standing congregations but share or rent from American congregations, who need income to supplement their declining membership. During the immigration influx of the 1970s and 1980s, the role of pastors shifted considerably from traditional pastoral care to providing social services for new immigrants. The activist role of pastors and social opportunities within the church groups have encouraged nearly 50% of Koreans in Chicago to be active in their churches. Churches are the primary social organizations in the Korean-American population.

According to the 1990 Census, 33,465 Korean-Americans live in the immediate Chicago metropolitan area, with nearly 20,000 living in the suburbs. Korean-American residents in the city are found on the north side neighborhoods of Albany Park, North Park, Rogers Park, and Uptown. In the north and northwest suburbs, Koreans have settled in Arlington Heights (510), Glenview (1,043), Hoffman Estates (673), Mount Prospect (746), Niles (586), Schaumburg (906) and Skokie (2,156). They also have substantial numbers in Lake County (1,923) and Joliet (408).

6. Vietnamese-Americans

According to the 1990 Census, there are 7,313 Vietnamese in the immediate Chicago metropolitan area, comprising 3.21% of the overall Asian-American population. This population is part of the exodus of refugees who fled Vietnam after the fall of Saigon and the U.S. military withdrawal in 1975. In the decade that followed more than two million people tried to escape, more than a million succeeded and the majority of whom have resettled in the United States.

The peoples of Vietnam are very diverse ethnically. The largest minority are Chinese, followed by more than 30 distinct tribes of mountain people. The Vietnamese refugee community in Chicago is very diverse as well. The early refugees were predominantly western-educated military officers, professionals, entrepreneurs, and landowners who fled at the fall of Saigon and the U.S. withdrawal in 1975. In the late 1970s and 1980s, the refugees also included poorer and more traditional farmers and fishermen from all regions of Vietnam. Most Vietnamese are Buddhist, but Catholicism, first introduced in the 16th century by European missionaries, has a sizable following among Vietnamese in Chicago.

One of the legacies of the Vietnam War are large numbers of children of U.S. soldiers and Vietnamese mothers -- identified as Amerasian. Born in Vietnam at the height of the Vietnam War in the late 1960s and early 1070s, Amerasians have endured much suffering, from their birth to their recent resettlement in the United States. In Vietnam, Amerasians and their mothers are subjected to widespread prejudice, discrimination, and persecution. They have been denied access to education and are illiterate in their own native Vietnamese. Some are shunned by their families and live on the streets. In 1988 the U.S. government enacted the Amerasian Homecoming Act which has facilitated the immigration of Amerasian children and their family members. Amerasians and their family members living in Chicago number nearly 1,000. Their resettlement process is particularly traumatic since many Amerasians come with dreams of being reunited with their fathers and instead experience rejection.

The majority of Vietnamese in the Chicago area live in the city of Chicago (4,620). Most live in close proximity to the Vietnamese shops, restaurants, grocery stores and Buddhist temples on Argyle Street in Uptown. In addition to Uptown, many Vietnamese live in the north side Chicago neighborhoods of Edgewater, Albany Park, and Rogers Park.

7. Cambodian-Americans

Cambodians in the Chicago metropolitan area total 2,456 persons, comprising approximately 1% of the overall Asian-American population. Like the Vietnamese, Cambodians are refugees from the wars in Southeast Asia. The Vietnam War spread to Cambodia in the late 1960s and 1970s. In 1975 after the takeover of the Khmer Rouge, there began four years of repression, reactionary policies and the genocide of more than a million Cambodians. The Khmer Rouge's regime was overthrown in 1979 by a Vietnamese occupation army and a Vietnamese sponsored government was initiated. During this period and in the decade afterwards, Cambodians fled to the Thailand and eventually were resettled in the United States. In Chicago, more than 2,000 Cambodians are scattered in other sections of north side Chicago and the suburbs of Joliet, Naperville, Glendale, and Wheaton. Many Cambodian men and women are employed in janitorial services, as assembly line workers, and some in a variety of professional/technical fields.

Cambodians speak the Khmer language. Most Cambodians are followers of Therevada Buddhism. Most Cambodian Buddhists belong to the Argyle Street Temple or the Winthrop Avenue Temple where a total of eight to ten monks reside. Cambodian laity have strong ties to the monks who not only provide spiritual instruction but also social roles. In the 1960s in Cambodia, many young Cambodian males spent some time in a temple or monastery learning the traditionally proper way to live. Monasteries served not only as religious sanctuaries but also as centers for education, culture, recreation, health, and social services. In Chicago today, the monks provide religious education and counseling in addition to ritual services. An increasing number of Cambodians also belong to the Uptown Baptist Church.

8. Laotian-Americans

In the 1990 Census, the Laotian population numbered more than 3,000 in the entire six collar county Chicago region. Laotians, like the Vietnamese, have come as refugees of the Vietnam War which in the 1960s spread to this inland nation wedged between Vietnam and Thailand. In 1975 the pro-Communist Pathet Lao took power and began a campaign of bloody repression; the groups supporting the United States scrambled in panic for safety. The Hmong, a minority group supporting the United States, suffered terribly in the imposition of Communist rule. Thousands of Hmong men had in the early 1970s joined a secret CIA-funded guerrilla army. Some 70,000 ethnic Lao and 60,000 Hmong fled to the U.S. Both the Laotians and Hmong were small peasant farmers in their homeland and had little formal education in their native languages -- Hmong or Lao -- as well as the colonial language, French. In the United States, the Hmong and Lao have had a difficult time adapting to industrialized, urban cultures. Some have found work in service industries and factories, some have tried to farm and work as farm laborers. The Hmong women have been particularly successful in making handicrafts.

Like the Cambodians, the Lao are predominantly Therevada Buddhists. However, the more indigenous spiritual/medical concepts of *phi* doctrine have fused with Buddhist teachings. The phi doctrine is based on the idea that 32 spirits rule the 32 organs of the body. In addition to the spiritual instruction sought from Buddhist monks, Laotians rely on elders who perform ceremonies, principally the *Baci*. The Baci is a ritual to call back all 32 spirits that inhabit a healthy human body. A host of ills (sickness, depression, bad-luck, etc.) can be explained by the absence of one or more spirits from the body. A Baci may be held at a variety of times and form the core of every popular celebration -- from weddings, births, deaths, to New Year. However, the community may also gather for a Baci to be performed for the benefit of a specific person.

Many of the Hmong who originally came to Chicago for initial resettlement have left for larger communities in California, Minnesota, and Wisconsin. The handful of Hmong remaining and a larger number of Lao (703) live in the north side neighborhoods of Uptown and Albany Park areas. Many Lao live in one of the resettlement areas in the northwest suburbs; in Elgin, Laos are the largest Asian group, with nearly 1,500 Laotians living there.

B. Methodologies and Findings

This section discusses the methodologies and findings of the needs assessment of Asian-Americans with developmental disabilities conducted by Asian Human Services of Chicago over a year period of time. An initial letter announcing the study was sent to 150 Pan Asian community organizations, temples/mosques/churches, local agencies supporting people with disabilities and peer social service agencies in the Chicago area (See Appendix 1). The needs assessment was comprised of three phases aiming to gain as complete information as possible from multiple parties involved in the social service delivery system for Asian-Americans with developmental disabilities in the Chicago area (See Table 2).

The main purpose of the present study can be summarized in three domains: 1) To gain identifiable prevalence of developmental disabilities among Asian-Americans in the Chicago area and an understanding about social service utilization patterns by diverse Asian-American ethnic groups; 2) To gain understanding about difficulties and barriers encountered by Asian-Americans with developmental disabilities when utilizing social services available and factors leading to underutilization of the resources in the mainstream and community service delivery systems and the community resources; 3) To make recommendations and suggestions on the basis of the appraisal of their special needs for effectively working with and reaching out to this population.

In order to achieve these goals, information was gained, during the three phases of the study, through three different sources involved in the service delivery for Asian-Americans with developmental disabilities: 1) Social service providers working in the mainstream service delivery systems for people with developmental disabilities; 2) Social service providers working in the Asian-American ethnic community service agencies; 3) Some Asian-American individuals and families affected by developmental disabilities. The information from the first two sources was gained mainly by mailed survey and the information from the third source was gathered by individual interviews and focus group meetings.

Table 2. *Three Phases of Needs Assessment of Asian-Americans with Developmental Disabilities in the Chicago Area*

Phase I

Participants/Methods:	Survey of 112 mainstream social service providers
Results:	44 surveys returned (40% response rate)
Period:	October, 1995 - December, 1995

Phase II

Participants/Methods:	Survey of 37 community social service providers
Results:	11 surveys returned (29% response rate)
Period:	January, 1996 - February, 1996

Phase III

Participants/Methods:	Individual Interviews with Asian-American families with a family member with a developmental disability and focus groups with Asian-American families
Results:	4 individual interviews and the focus group with 4 families and a community service provider
Period:	February, 1996 - April, 1996

Phase I: Survey of the Mainstream Social Service Providers

Purpose of the Study

The primary goal of this survey was to gain information in the following four areas: a) the current estimated prevalence of developmental disabilities among Asian-Americans in the Chicago area and their social service utilization patterns; b) the mainstream social service providers' reports of difficulties when working with Asian-American clients with developmental disabilities and their families; c) the mainstream social service providers' perceptions about barriers encountered by Asian-Americans with developmental disabilities and their families and d) the mainstream social service providers' suggestions and recommendations for more effectively working with and reaching out to this population.

Procedure of the Study

The survey questionnaire was developed to achieve the four aforementioned goals (See Appendix 2) and was sent to the 112 mainstream social service agencies in the Chicago area. These 112 agencies were selected from the subject index under developmental disabilities listed in the 1994-1995 Human Care Services Directory of Metropolitan Chicago. Starting with the question of whether the agency currently has Asian-American clients with developmental disabilities and providing definitions of Asian-American and developmental disabilities, the survey questions ask the respondents to indicate the actual and estimated number of Asian-Americans receiving services at their agency.

Next, a Client Report Form was designed to be filled out with specific information about these Asian-American clients (i.e., age, gender, ethnicity, type of disability, severity of disability, and services provided). Three open-ended questions followed the Client Report Form to generate descriptive information about three issues: 1) difficulties and issues experienced by the service providers or their agency when working with Asian-American clients with developmental disabilities; 2) difficulties and barriers encountered by Asian-American clients with developmental disabilities in the process of utilizing the services at their agency and 3) special needs of this client population and recommendations for more effectively working with and reaching out to them. In addition, the respondents were requested to indicate their willingness to help plan focus groups which would be run at the latter stage of the study if some of their Asian-American families of clients would be willing to participate.

Since the survey questionnaire was designed to be filled out by the service provider who has had some past or current direct experiences working with Asian-Americans at the agency, it was sent to the director of the agency who was then requested, after reading the cover letter, to give the questionnaire to the staff member who would be able to provide the required information about the Asian-American clients at their agency. A separate cover letter for the actual respondents to the survey was attached with the survey questionnaire explaining the purpose of the study with specific instructions for the survey. A self-addressed envelope was also enclosed.

A month later, a follow-up letter was sent to the same 112 agencies encouraging an immediate response to the survey.

Results and Findings

Out of the 112 agencies where the survey questionnaire was mailed, 44 agencies in total returned their survey (40% response rate). Among 44 responses, 12 agencies reported that they did not have any Asian-American clients at the time of the survey, and 32 agencies provided either an estimated or actual number of Asian-American clients with developmental disabilities who were receiving services at the time of the survey at their agency. Appendix 3 provides information regarding the names and addresses of these 32 agencies which reported having Asian-American clients. It also shows the estimated or actual number of Asian-American clients currently utilizing some form of services at each agency.

A. Characteristics of Asian-Americans with Developmental Disabilities Who Are Currently Utilizing Services at the Mainstream Social Service Agencies

The total number of Asian-American clients with developmental disabilities who were utilizing some type of services at the mainstream social service agencies at the time of the survey was 94. The number increases to 104 if the estimated numbers are added. Table 3 shows some descriptive information about these Asian-American clients such as age, gender, ethnicity, type of disability, severity of disability, and type of services utilized by them.

Table 3. *Asian-Americans with Developmental Disabilities Currently Utilizing Services at the Mainstream Social Service Agencies*

Total Number of Asian-American Clients Reported:

N = 94 (Actual)
N = 104 (Estimated)

Age:

Range = 1-38 years old
Mean = 16.70 years old
Median = 16 years old
Mode = 2 (Frequency = 6), 15 (5) , 23 (5) years old

Gender:

Male	N = 60	64 %
Female	N = 34	36 %

Ethnicity:

Asian Indian	N=19	22 %
Chinese	N=18	19 %
Filipino	N=14	15 %
Korean	N= 9	10 %
Japanese	N= 7	7 %
Vietnamese	N= 5	5 %
Pakistani	N= 5	5 %
Amerasian	N= 2	2 %
Thai	N= 1	1 %
Cambodian	N= 1	1 %
Syrian	N= 1	1 %
Unreported	N=12	13 %

Type of Disability:

Mental Retardation	N=61	65 %
Autism	N= 9	10 %
Cerebral Palsy	N= 4	4 %
Epilepsy	N= 4	4 %
Down Syndrome	N= 4	4 %
(Developmentally Delayed)	N=11	12 %
(Physically Disabled)	N= 1	1 %

Severity of Disability:

Severe	N=29	31 %
Moderate	N=20	21 %
Mild	N=21	22 %
Cognitively Intact	N= 4	4 %
Unreported	N=20	21 %

Types of Services Utilized:

Developmental Training	N=24	26 %
Vocational Training	N=24	26 %
Nursing/Habitation	N=11	12 %
Academic Education	N=11	12 %
Recreation	N= 8	9 %
Respite	N= 5	5 %
Case Management	N= 2	2 %
Family Support	N= 2	2 %
Physical Therapy	N= 2	2 %
Early Intervention Program	N= 1	1 %

Speech Therapy	N= 1	1 %
Unreported	N= 1	1 %

The mean age of the reported Asian-American clients with developmental disabilities was 16 while the age ranged from 1 to 38. Sixty-four percent of them (N=60) were male and 36 % were female (N=34). The proportion of each Asian ethnic client population reflected the overall proportion of these groups in general population in the Chicago area. Asian Indian was the largest client population (22 %) followed by Chinese (18%) and Filipino (15%). The Korean and the Japanese groups consisted of 10% and 7% of the total number respectively. The Vietnamese and the Pakistani groups consisted of 5% respectively followed by the Amerasian, the Thai, the Cambodian, and the Syrian that were reported to be under 2%. Mental retardation was the most dominant type of developmental disability (65%) among the reported Asian-American clients followed by autism (10%). Cerebral palsy, epilepsy, and Down syndrome were equally reported as comprising of 4 % of the Asian-American clients. Forty-one percent of them were reported having severe disability while 21% and 22% of them have moderate and mild disability respectively. Developmental training (26%) and vocational training (26%) were the most frequently reported forms of service utilized by the Asian-American clients. A variety of services appeared to be utilized by the reported Asian-American clients with developmental disabilities.

B. Mainstream Service Providers' Reports of Issues and Difficulties Experienced When Working with Asian-Americans with Developmental Disabilities

The following section presents the findings resulting from the analysis of responses provided by the 32 mainstream service providers to the following open-ended question in the survey: "what are some difficulties and issues that you and your agency have experienced when working with Asian-Americans with developmental disabilities and their families?" Quoted statements were directly taken from their responses to the survey and *italics* in the parenthesis were added to the original statements for conceptual clarity.

1) Communication Difficulties due to Language Differences

Fifty percent of the respondents indicated that language barriers were the major source of difficulties when working with Asian-Americans with developmental disabilities and their families. Difficulties due to language differences were most frequently reported as interfering in the various stages of service delivery: The initial assessment of a disability, understanding of a disability, decision making for treatment, utilization of social services, and so on.

* "Language barriers -- especially when it comes to intervening with clients and families and when testing clients."
* "Difficulty in completing an accurate and full assessment and/or needed testing."
* "Inability to speak the language which effect their medical treatment, ability to get and keep a job, community integration, etc."

The service providers seemed to try to partly overcome the communication barrier when working with Asian-American clients and their families by attempting to utilize translation services. However, their report indicated that it is additionally difficult to locate a translator in their regional area for an Asian-American client whose English is not fluent. They reported that locating a bilingual Asian-American translator was challenging and sometimes unsuccessful since the Asian -American population is a minority in their regional area and there are diverse dialects even in one specific ethnic language.

* "Communication difficulties remain a primary concern. It is often difficult to help a family to accept a child's disabilities. When English is a second language, communication is an additional challenge. In this area *(Joliet)*, interpreters for Asian languages are not plentiful."
* "Language barriers -- no one available to interpret as there are so many different dialects."
* "The guardian of one client has difficulty with English. We had looked, unsuccessfully, for a Vietnamese translator."
* "It has also been frustrating for the families, since we are often without interpreters both for discussion and for documents which impact on the treatment their child receives. Because of the population which we serve *(early intervention program)*, we are often the first persons to talk to parents about Cerebral Palsy or other diagnoses. This painful experience is made worse when parents do not understand the language and can't ask questions."

The reported frustration is mutual on the service providers and the recipients with one respondent indicating that Asian-American clients might feel more stressed since English is the expected communication language.

* "Some have taken English as a second language, did not do well (their report), unwilling to repeat -- said it was too stressful."

As an alternative to verbal communication which remains a serious and persistent barrier, one respondent reported that the employment of services utilizing nonverbal forms of communication might alleviate Asian-American clients' initial reluctance and anxiety level created by the language differences.

* "We utilize play and since play and fun is universal the clients are able to utilize our services. Sometimes telephone communication is somewhat difficult."

2) Issues related with Perceived Cultural Differences

Cultural Uniqueness of Asian-Americans

Some respondents reported that cultural differences between service providers and Asian-Americans do not necessarily create difficulties but offer an unique experience to

mainstream service providers. On the other hand, one response reflected that cultural differences may not be always recognized as related to the difficulties service providers experience, suggesting that other factors such as the communication difficulty is the most manifest barrier.

* "I don't find cultural difference difficulties, but things are interesting and unique. Need for many members of extended family to be involved and have information about program/services before family feels comfortable."
* "Privacy of family life -- interesting."
* "I personally have not noticed any cultural difficulties beyond some minor communication gaps with the family."

Family-related Issues: Intergenerational Support and Expectations

The most frequently reported cultural aspects of working with Asian-American clients and their families seemed to be drawn from the mainstream service providers' observations on Asian-American clients' family interactions. The respondents perceived that Asian-American families' intergenerational ties are quite strong and supportive, and each generation and each family member holds culturally unique, assumed roles and expectations. It was also observed that family members seem to fulfill these intergenerational and familial expectations with a strong sense of "duty."

* "We found that the families are very supportive and close."
* "Seemed to have dual income families, some with parents working third shift with help from grandparents for day care."
* "Some families had great expectations and perhaps pushed the children to excel to meet their full potential. Some families were hesitant to use professional services for respite so care givers never got a break -- "duty" issues here."

Gender-related Issues: Sex-role Differences

Within the context of familial expectations and duties of fulfilling family roles, some respondents reported that gender of family members might determine the assuming roles of care needed to be provided to a family member with a developmental disability. While the respondents showed their ongoing struggles to understand if this gender differences in family interactions are due to clients' Asian cultural background or the unique interaction patterns in each family, it was perceived that cultural socialization process might be responsible to some degree for the differences in gender-related roles.

* "I am reluctant to generalize but -- mothers seem to get very little support from fathers who tend to deny problems exist. Fathers are condescending to female staff. **Staff are unsure whether some issues are cultural or just unique to that family**."
* "Cultural differences; i.e., in some cultures the women do not socialize with the men and it is difficult to integrate them with groups of both sexes."

Differences in Viewing Disabilities

One respondent reported that their Asian-American clients view disabilities differently than the majority population due to their cultural background without elaborating upon the perceived differences in viewpoints. However, the response reflected that the Asian-American clients' viewpoints might be affected by their need for privacy.

* "Their culture is so different -- they view disabilities in a completely different manner. They are usually very private people."

Gap between Perceived Needs and Actual Needs due to Unknown Cultural/Ethnic Differences

One respondent indicated that invisible or unknown cultural and ethnic differences might create difficulties because of the gap between service providers' assumptions of developmentally disabled individuals' universal needs and Asian-American clients' actual needs. These unknown factors related to cultural differences might include Asian-American clients' status as immigrants whose interests and concerns rest in their native country.

* "I think always persons and agencies need to meet the needs of individual and persons they serve. Sometimes there are bigger gaps or unknown issues due to cultural difficulties."
* "*(We)* provided individual counseling on an as needed basis to help one person deal with problems occurring in the person's homeland -- earthquake, political upheavals, etc."

3) Other Difficulties When Working with Asian-American Clients

There were some responses that indicate somewhat the nature of the difficulties mainstream service providers might experience when working with Asian-American clients. These difficulties, however, were not able to be clearly identified as stemming from either the communication difficulty or cultural differences. The difficulties included the following: (a) coordinating and expanding service utilization in the full range of service delivery system; (b) inefficiency due to Asian-American clients' reluctance to utilize some necessary additional services such as translators; (c)completing a thorough examination and assessment of a disability; (d) engaging Asian-American clients in necessary administrative procedures such as "paper work" required by the government.

* "*(a)* Unable to coordinate medical appointments or referrals to other health related resources; *(b)* Non-compliance with care plan due to reluctance to use interpreters, transportation and culturally sensitive staff; © Difficulty in completing an accurate and full assessment and/or needed testing."
* "*(d)* Difficult when dealing with the social service agencies as it takes time to explain the process of government and "paperwork" when is essential to provide services which are needed."

C. Mainstream Service Providers' Perceived Issues and Difficulties Experienced by Asian-American Clients

The following section presents the findings resulting from the analysis of responses provided by the 32 mainstream service providers to the following open-ended question in the survey: "what are some difficulties and issues that Asian-Americans with developmental disabilities and the families themselves have, possibly due to their cultural/ethnic backgrounds or language differences, in the process of utilizing the services at your agency?"

1) Difficulties due to Language Differences

Language differences were reported as the foremost difficulty that Asian-Americans with developmental disabilities might experience in the service delivery system. Language difficulty was presented to be operating in three domains. One domain reflects the difficulty Asian-American clients might have when informed of the nature of a developmental disability in the second language while the other reflects the understanding of the services available to them. One response especially implied that the initial understanding of a developmental disability such as Down Syndrome is challenging to some Asian-American clients because the nature of such disability is not well documented in their own native language. The third domain, actual utilization of the services, seemed to be another challenge to some Asian-Americans with limited English.

* "Language is sometimes a barrier."
* "Language barriers."
* "Some communication difficulties (language differences)."
* "There is no material regarding Down Syndrome in their own language."
* "With the language barrier it is difficult to explain the services they are entitled to."
* "Language difficulties rather than cultural differences seem to present a barrier to utilizing services that are available. Genuine concern and a willingness to comply with instructions seem to be present."

2) Lack of Knowledge on the Nature of Developmental Disabilities and the Mainstream Service Delivery

Differences in Conceptualizing Disabilities

There is an indication that some Asian-Americans might understand developmental disabilities in a different manner from that of the majority, possibly due to the cultural differences and the lack of information about disabilities in their own native language.

* "Their culture is so different -- they view disabilities in a completely different manner."
* "There is no material regarding Down syndrome in their language."

Lack of Knowledge on the Mainstream Service Delivery System

Possibly due to language barriers, cultural uniqueness, and educational level, some Asian-Americans seemed to have limited understanding about health care practices in general and treatment procedures for developmental disabilities in particular in the mainstream service delivery system. The lack of understanding of the general American health practices and systems seems to discourage some Asian-Americans to advocate for family members with a developmental disability.

* "Limited understanding due to education, language and culture barrier."
* "Non-compliance/refusal of testing and follow-up visits due to knowledge deficit related to American health care system."
* "The ability to comprehend and then advocate for their child is challenge for most Asian-American families."

Lack of knowledge of general health care system in the United States might also result in misunderstanding and create confusion on some specific principles and procedures practiced in the mainstream social service delivery system. Recent Asian-American immigrants might have more difficulty understanding American health care system which is different from the one in their native country.

* "Asian-Americans seem to have an expectation that services should be free of charge even when they have middle class incomes, "government" should pay -- especially those newer to the country."

However, it was also observed that there is a willingness among Asian-Americans to understand the mainstream service delivery system which is new to them and to comply with the required procedures.

* "Genuine concern and a willingness to comply with instructions seem to be present."

3) Cultural Issues

Importance of Privacy in Family Life

The importance of privacy in family life seemed to be recognized by many mainstream service providers as a cultural characteristic of Asian-Americans. The responses reflected that Asian-Americans may be less likely or hesitant to reveal their family histories or issues to other client families as well as to service providers which are necessary to incorporate them into making treatment plans.

* "Privacy of family life -- interesting."
* "Reluctance to divulge information (e.g., social histories, medical histories)."

* "Because of their privacy -- we are unable to draw upon them as future support for other families of the same culture when new babies are born."

Family Responsibilities

Some service providers felt that some of their Asian-American client families have a strong sense of "duty" and "responsibility" for taking care of their family member with a developmental disability on their own. Their strong need to assume responsibilities for the family member with the developmental disability and to rely on internal resources within family, might adversely result in their underutilizing, or further rejecting, effective external social services which are designed for and available to them.

* "Some families were hesitant to use professional services for respite services. Care givers never got a break -- "duty" issue here."
* "Reluctance to utilize services (e.g., residential placement, social activities) because family chooses to assure responsibilities."

Intergenerational Expectations

It was also observed that some Asian-American families might have high expectations for their offspring to fulfill. However, without fully considering the limitations caused by developmental disabilities, aspiration for their children's success might cloud their understanding of the nature of the disabilities and the extent to which the disabilities might adversely affect their children's development and potential for future functioning.

* "Also some families tend to have high expectations for their offspring and they are less accepting of disability-related issues."

Gender-Related Issues

Asian-American female caretakers for family members with developmental disabilities, primarily mothers, seemed to have difficulties due to the lack of practical survival skills and the scarcity of resources in the family. Female caretakers who do not know how to drive or are unable to arrange transportation for the family at their convenience might feel unsupported and disconnected in her social life.

* "Mothers often do not drive or have transportation available. Sometimes appear to be isolated."

Misunderstanding of Mainstream Services

A few service providers felt that some Asian-Americans might hold misconceptions about the Western medical practices, favoring their traditional Asian treatment modalities. The respondents

reported that these attitudes lead to mistrust toward medical and psychological professionals and create resistance to Western medical treatment such as medication.

* "Medication non-compliance due to misconception of Western medicine. Families encourages herbal medicine and ancient treatment."
* "Some distrust at psychologist/psychiatrists."

4) Being a Minority in the Service Delivery System

Not only being an ethnic minority in the general population, but also being a minority client population in the service delivery system for developmental disabilities seems to operate as another barrier to Asian-Americans. One respondent indicated that Asian-Americans with developmental disabilities might feel estranged and stigmatized due to the current small percentage of Asian-Americans with developmental disabilities utilizing services in the mainstream service delivery system.

* "The main difficulty for them (I think) is the fact that we do not have a large population of other Asian-Americans receiving services. I think this increases a sense of isolation and shame about their situation."

5) Within-Group Differences among Asian-Americans

One respondent reported that the difficulties experienced by Asian-Americans in utilizing social services might be more complicated because they have to deal with barriers caused by language and cultural differences not only when interacting with mainstream service providers but also when relating to other Asian-American families from different ethnic origins for support and group services that may be offered by the agency. Asian-Americans' difficulties seem to be further exacerbated the universal barriers caused by disabilities per se within the general service delivery system as well as interpersonal difficulties caused by their within-group differences when treatment situations require them to interact with different Asian ethnic groups. However, when the language barrier is overcome to the point that the caregivers from different ethnic groups can communicate with each other, they appear to be of great support to themselves.

* "Our agency tries to make our services as accommodating as possible to support the unique person and each family. The difficulties I have observed have been interpersonal (*Asian-American* client to client) due to cultural/ethnic/language difficulties compounded by developmental disabilities."
* "In general moms seem to enjoy being with other moms when language barrier can be breached."

6) Lack of Resources in Family

It appeared that one of the serious difficulties experienced by Asian-American families with members who are developmentally disabled is the scarcity of internal resources in the family.

Partially for those families in which both parents must work to provide basic necessities, there does not seem to be enough spare time for the child with a developmental disability. The scarcity of economic resources might present multiple difficulties to the families in assuring adequate and sufficient medical care and other social services in addition to securing enough time for attending to the child with a developmental disability. This difficulty might be aggravated when other sources of family support are unavailable.

* "Economic resources inadequate for medical needs."
* "Parents having to work 2 or more jobs so little supervision at home and diminished ability to help sons or daughters with epilepsy."
* "Seemed to be dual income families, some with parents working third shift and help from grandparents for day care."

D. Suggestions and Recommendations for Effectively Working with and Reaching Out to Asian-Americans with Developmental Disabilities

The following section presents the findings resulting from the analysis of responses provided by the 32 mainstream service providers to the following open-ended question in the survey: "what kinds of issues do you think should be considered when working with Asian-Americans with developmental disabilities and their families? Please feel free to indicate any suggestions and recommendations for more effectively working with and reaching out to them."

1) Increasing Cultural Sensitivity of Mainstream Service Providers

Need for Being Sensitive to Ethnic/cultural Differences

Five respondents indicated that due to their limited experience of working with Asian-American clients at their agencies, they are not well aware of unique issues or special needs that Asian-Americans with developmental disabilities might have. Although they recognized their limited knowledge about Asian-Americans with developmental disabilities, they showed an interest and willingness to gain information about this population.

* "As we have never served Asian-American families we are unaware of any cultural issues unique to Asian-American families. We would be interested in any information that would aid us, should we serve this population."
* "Asians make up a very small percentage at our total *(client)* population."
* "Our experience of working with the Asian-Americans with developmental disabilities has been very limited."
* "Our agency does not serve enough of the Asian-American population for me to be completely thorough with this survey."
* "I don't feel that I know enough about Asian-Americans to answer this question."

Many service providers recognized that it is important to take into account ethnic/cultural issues and the language barrier when working with Asian-Americans with developmental disabilities and making treatment plans for them. They emphasized that service providers working with Asian-Americans with developmental disabilities should be aware of treatment process issues that might arise from ethnic/cultural differences and language differences and then provide services tailored to the special needs of Asian-Americans.

* "Understanding of the specific ethnic/cultural issues."
* "Any cultural differences and language barriers should be considered and planned for."
* "Communication on any level is essential in best understanding the person with a disability. It is important to allow for individual as well as cultural differences and more importantly, to share and learn to appreciate and grow from these differences."
* "Be aware of cultural differences and respect the differences as well as provide services in accordance with cultural differences."
* "Learn what is important to them and respect that."

Need for Understanding Specific and Unique Ethnic/Cultural Issues

Many respondents, on the basis of their working experiences with Asian-American clients, provided specific suggestions for ways of working with Asian-Americans which might be culturally sensitive and therefore therapeutically effective. These suggestions broke down into two domains: (1) Culturally sensitive treatment plans and processes and (2) some knowledge of particular Asian cultures useful to understanding the meanings of these Asian-American clients' behaviors and assets. Addressing number one, some responses reflected specific suggestions for more efficient treatment procedures such as arranging for trained translators, considering the primary caregiver's working situation particularly of recent Asian-American immigrant, and identifying a chief decision maker in family who may be possibly different from the primary caregiver.

* "To provide culturally sensitive and trained medical interpreters for better outcome, compliance and effective care."
* "To work with medical staff in order to accommodate family's working schedule and to eliminate unnecessary visits and testing to reduce financial burden."
* "To identify family decision maker in less time by communication with family through more efficient means."

Addressing number two, some responses showed a deeper understanding about the importance of some cultural traits germane to Asian-American clients ethnic backgrounds. These cultural implications included the importance of family privacy, diverse religious beliefs, hierarchy in the family, and generational role assumptions within the family.

* "Always respect their right to privacy."
* "Acknowledge cultural and religious differences/beliefs."

* "Agency needs to be aware of the meaning of the arrangements of their (Asian-American) names (what we may translate as their last name may not be)."
* "Our families have been extremely helpful to us in sharing traditions, role assumptions within the family (grandmother's role with child -- able to respect that by suggesting "her" things such as massage, etc. -- The entire family have participated, we've learned a lot."

Family-Related Cultural Issues

Some respondents reported their observations of some qualities of family interactions distinctive to Asian-American clients. These qualities appeared to include issues of respect for family hierarchy, interdependence among family members and between generations, and parents' sense of responsibility and aspiration for their children which might be seen in their seemingly overprotective behaviors toward their child with a developmental disability. The respondents emphasized, in addition, that these qualities should be understood by service providers from the Asian-American cultural perspectives rather than judged by the normative mainstream cultural practices.

* "I think we non-Asian-Americans need to understand better the way families work in different cultures (i.e., issues of respect, of independence/interdependence, etc.) so that we can be sure to honor these qualities rather than impose our "standards" or beliefs."
* "Overprotectiveness of their son/daughters."

Individual Differences

Finally, one respondent's observation signified that the generalization of any of these commonly perceived cultural traits and qualities in Asian American communities to all the Asian-American client population may not be suitable because individual and family differences always exist. Each Asian-American individual and family is unique and this plays a significant role in the design of effective therapeutic approaches.

* "In our experience each family has been different in what worked."

2) Overcoming Language and Communication Barriers

Need for Translation Services

Many respondents strongly recognized their need for translation services when working with Asian-Americans with limited English. They reported that translators or translation services might greatly assist the treatment decision process.

* "Interpreters would be of valuable assistance."
* "Would be nice to have translators available."
* "Translation services is a need we have seen."

In addition, one respondent strongly implied that highly educated bilingual Asian-American professionals engaging in the medical and mental health professions would be of great help to the mainstream service providers due to their higher level communication skills, resulting in better treatment plans for Asian-Americans with developmental disabilities. The respondent also urged bilingual Asian-American professionals to engage in providing various services necessary for the lower socioeconomic Asian-Americans with developmental disabilities.

* "Professionals, i.e., doctors, lawyers, dentists, psychologists, therapists who speak specific languages (i.e., Tagalog, Urdu) to assist us and the client would be helpful, also professionals who would serve lower socioeconomic clients."

Continuing Language Education

Providing only translation services to Asian-American clients on a needed basis may not reduce the main problems embedded in the language differences between the mainstream service providers and Asian-American clients. One respondent, thus, encouraged Asian-Americans to continue to improve their own English proficiency.

* "ESL to assist people to understand English better."

Alternative Approach to Overcoming Language Barriers

On the other hand, as an alternative way of overcoming the language barrier, one respondent suggested that other aspects and modes of communication for making connections with people from different cultures, such as humor, could be appropriately utilized as an addition to the typical communication mode.

* "My suggestion is to use humor when appropriate -- it is the universal language."

3) Organizing Community-based Resources

Organizing Resources in Asian-American Community

Many respondents emphasized that Asian-Americans should take the initiative in organizing resources in the Asian-American community. One of the common suggestions was that "a directory of resources" should be constructed that would help and guide both the families of Asian-Americans with developmental disabilities and the mainstream service providers to gain necessary information and services. The suggestions reflected that this task should be achieved by a central agency primarily serving diverse ethnic groups of Asian-American population, for instance, Asian Human Services of Chicago, functioning as a clearinghouse.

The responses suggested that this type of resource book should include several domains of information. First, it was suggested that some help be given to Asian-Americans in locating other

Asian-American families affected by these disabilities. Then more general information should be organized according to the type of disability, ethnicity, native language spoken, and so on. This directory would be helpful when some families want to share with or need some information from the families who are in similar circumstances. Ultimately, the systematic identification of all Asian-American families with members who are developmentally disabled will lead to strengthening the network and support system in the Pan-Asian community.

Second, in addition to the information about those Asian-American families who are willing to share their experiences in taking care of their family members with developmental disabilities, some providers suggested that the resource book should include formal and informal means of obtaining bilingual translators competent in each Asian ethnic language. One respondent also suggested that information about bilingual Asian-American professionals engaging in the medical and mental health disciplines should be collected and organized so that this list could be available to the mainstream service providers when consultation is needed for better cultural understanding and overcoming language restrictions.

In addition, as the arrangement of transportation was regarded as one of the difficulties experienced by the Asian-American families having a family member with a developmental disability, one respondent suggested that information about transportation services should be included in the resource book so that it could be available to both Asian-American families who need this service or the mainstream service providers who wish to arrange it for their clients.

* "It would be nice if Asian people would reach out to help each other. They themselves have to become resources to each other. It would be great of you could organize groups according to ethnicity and disabilities -- so that there would be resources available. Just to group together as "disabilities" would not be effective as if you could group them as "Down syndrome group," "Autistic," etc."
* "**A directory of resources** which would provide services with these cultural and language differences would be helpful."
* "Professionals, i.e., doctors, lawyers, dentists, psychologists, therapists who speak specific languages (i.e., Tagalog, Urdu) to assist us and the client would be helpful, also professionals who would serve lower socioeconomic clients."
* "In our area *(Joliet)* the Asian-American population requiring services is limited. **Linking families with an agency/clearinghouse** that could serve as a liaison would be beneficial. An outreach from Asian Human Services, or another agency able to provide translators' transportation, etc. would enable agencies working with Asian-Americans to access assistance.
* "My agency in particular needs assistance working with the families of the clients we serve. We serve a population of children from 0-3 yr. Our main problem is eliciting participation from the parents as the law mandates us to do. It would be extremely helpful if your agency could assist us in locating other families with children with developmental disabilities that could network with our families. It would also be helpful if your agency could inform us of formal or informal ways of obtaining translation services for our Asian-American families.

4) Increasing Asian-Americans' Awareness of Mainstream Service Delivery System

Need for Developing Educational Programs regarding the Nature of Developmental Disabilities

It was observed by a respondent that some Asian-American families viewed the nature of developmental disabilities differently from the one shared by the majority culture and treated their family members with a developmental disability as having a "physical illness." The respondent indicated that any cultural differences in viewing developmental disabilities should be mutually explored and clearly known to the parties involved in the treatment process so that the gap in understanding of developmental disabilities between the mainstream service providers and Asian-American clients should not interfere with the initial diagnoses and treatment planning. Any educational programs aimed at increasing the awareness of Asian-Americans regarding services needed by people with developmental disabilities should also include information about the mainstream health care system in general.

* "We are not presently experiencing any issues with the parents of our current Asian-American clients. But in the past we had an Asian family which treated the client's illness in a way considered physical illness in our culture -- but was common custom in their culture. It should be of help if Asian-Americans could be made aware by an agency such as yours that they should share cultural differences or customs which result in school staff observing physical signs or behavioral differences in a student."

Need for Developing Educational Programs regarding Service Delivery System for Developmental Disabilities

In addition to becoming well aware of the basic notions about developmental disabilities embedded in the mainstream health care practices, Asian-Americans might gain great benefit from any educational programs aimed at disseminating information about the current procedures and practices of the mainstream service delivery for developmental disabilities, especially for those Asian-American families that have recently learned of their family members' having a developmental disability. Asian-Americans with developmental disabilities might gain more sense of control over determining treatment plans based on increased information about resources available to them.

* "It would appear based on the lack of request for service for Asian-Americans that they are unaware or reluctant to seek assistance or help. I would recommend that an educational program be developed to provide Asian-Americans with listings of the resources that are available to disabled individuals and new individuals with disabilities can access these services."
* "To educate the client and family members on the health care system, diagnosis, medication, treatments, and procedures required and methods for preventive care."
* "Better assurance or informed consent in order to prevent malpractice suits and time-consuming complaints."

Some respondents felt that educational programs should stress training Asian-American parents with a child having a developmental disability to be strong advocates for child's special education needs. This training emphasis, as a result, will help the parents secure the education to which their child is entitled.

* "Training on special education."
* "Training on special education -- disability rights."
* "Advocacy issues."

Phase II: Survey of Asian-American Community Service Providers

Purpose of the Study

The purpose of this survey was to gain understanding about a) the extent of service utilization by Asian-Americans with developmental disabilities at the Asian-American community social service agencies and the types of services utilized; b) the nature of formal or informal social support groups or service programs available to Asian-Americans with developmental disabilities in their own ethnic community; c) community service providers' perceptions about difficulties and barriers experienced by Asian-Americans with developmental disabilities; and d) community service providers' suggestions and recommendations for more effectively working with and reaching out to them.

Procedure of the Study

The survey questionnaire addressing the four aforementioned issues was developed and sent to 37 various ethnic community agencies and organizations serving particular groups of Asian-Americans living in the Chicago area (See Appendix 4). A cover letter was attached to the questionnaire highlighting the importance of the community service providers' response to the survey along with the statements of the purpose of the study. A follow-up letter was sent to the same agencies a month later.

Results and Findings

Out of 37 surveys that were initially sent, 11 surveys were returned in total (29% response rate). Appendix 5 lists the names and addresses of the Asian-American community service agencies that responded to the survey. Eleven agencies represented major Asian-American ethnic groups in the Chicago area: Vietnamese, Chinese, Korean, Cambodian, Japanese, and Tibetan. Among the 11 agencies, 4 agencies reported that they had Asian-American clients with developmental disabilities at the time of the survey who were utilizing some forms of services at the agency. These agencies include Vietnamese Association of Illinois, Chinese American Service League, Korean American Senior Center, and Asian Human Services of Chicago. The numbers of Asian-American clients at each agency were 8, 5, 4, and 6, respectively. The other 7 agencies indicated that they had no Asian-American clients with developmental disabilities utilizing services at the agency.

A. Extent of Service Utilization by Asian-Americans with Developmental Disabilities at the Community Social Service Agencies and the Types of Services Provided

The total and actual number of Asian-American clients with developmental disabilities who were utilizing some forms of services at Asian-American community agencies at the time of the survey was 23. The total estimated number, however, was 36. Table 4 shows some descriptive information about these clients' age, gender, ethnicity, type of disability, severity of disability, and type of services utilized by them.

Table 4. *Asian-Americans with Developmental Disabilities Currently Utilizing Services at the Community Social Service Agencies*

Total Number of Asian-American Clients Reported:

N = 23 (Actual)
N = 36 (Estimated)

Age:

Range = 3-50 years old
Mean = 24.53 years old
Median = 25 years old
Mode = 25 (Frequency=3), 3 (2), 46 (2) years old

Gender:

Male	N=12	52%
Female	N=11	48%

Ethnicity:

Chinese	N= 7	30%
Korean	N= 4	17%
Vietnamese	N=11	48%
Amerasian	N= 1	4%

Type of Disability:

Mental Retardation	N=15	65 %
Autism	N= 1	4 %
Cerebral Palsy	N= 4	17 %
Epilepsy	N= 1	4 %
Other	N= 2	8 %

Severity of Disability:

Severe	N= 6	26 %
Moderate	N=10	43 %
Mild	N= 4	17 %
Unreported	N= 3	13 %

Types of Services Utilized:

Information/Referral	N=8	35%
Vocational Training	N=2	9%
Homemaker Services	N=1	4%
Counseling	N=3	13%
Family Counseling	N=5	22%
Arranging for Community Care	N=1	4%
Arranging for Legal Services	N=1	4%
Entitlement	N=1	4%
Translation for Psychiatrists	N=2	9%

The mean age of the total 23 Asian-American clients reported by the four agencies was 24.53 while the age ranged from 3 to 50. Fifty-two percent of them (N=12) were male and 48 % of them were female (N=11). The identified ethnic backgrounds of these clients were 7 Chinese-Americans, 4 Korean-Americans, 11 Vietnamese-Americans, and 1 Amerasian. Seven (65%) of them have mental retardation and 4 have cerebral palsy. Autism and epilepsy were reported once respectively. Approximately half of the total clients (N=10, 43%) were reported having a moderate disability while 26% of them were reported as severe and 17% as mild.

The types of services provided to these clients were wide ranging: Information/referral, vocational training, counseling, family counseling, arranging for community care, arranging for legal services, entitlement, and translation services for psychiatrists. Most of these services, however, appeared to be characterized as indirect services addressing needs arising from their treatment services per se. This reflects that general Asian-American community service agencies function as assisting Asian-Americans with developmental disabilities to gain direct treatment services through providing referral services, arrangement of community care, translation services for psychiatrists, and legal services.

B. Formal or Informal Community Social Support for Individuals with Developmental Disabilities in Each Asian-American Ethnic Community

None of the respondents from the 11 agencies reported knowing of the existence of any formal or informal social support groups for individuals with developmental disabilities operated in their own Asian-American ethnic communities. Eight of them reported that they are certain that there are no such social support groups or service programs running in their ethnic community. Two respondents from the Korean-American Senior center and Immigrant/Refugee Area Health Education reported that they are not sure whether or not such programs exist in their own communities. It is not clear if these respondents' answers might accurately reflect the current status of formal and informal community support for people with developmental disabilities or might be incorrect due to their limited knowledge in this area. It was revealed, however, through some follow-up interviews with the community service providers that in the Korean-American community, there are two social support groups: one is for Korean-American individuals with developmental disabilities which is led by the Korean-American College Ministry and the other for Korean-Americans with various kinds of disabilities.

C. Community Service Providers' Perceptions about Barriers Encountered by Asian-Americans with Developmental Disabilities

Six community service provider respondents reported their perceptions about issues and difficulties that Asian-Americans with developmental disabilities and their families might have due to their ethnic/cultural background. Quoted statements were directly taken from their responses to the survey and *italics* in the parenthesis were added to the original statements for conceptual clarity.

Lack of Information and Knowledge of the Mainstream Health Care System

The main source of the concerns reported by the community service providers was the fact that the families of Asian-Americans with developmental disabilities lack information and knowledge of the health care system and resources available to individuals with developmental disabilities in the mainstream society as well as in the community. Recent Asian-American immigrants need to learn about the health care systems as practiced in the U.S. that are different from those operated in their native country.

* "Lack of information."
* "Difference in health systems."
* "Lack of knowledge in available community resources."

Lack of Resources within the Family and the Community

It was perceived that Asian-Americans with developmental disabilities have difficulties due to the lack of resources within the family as well as in the community. Internal resources within the family, such as time, finances, and transportation, might not be enough to provide necessary care for the family member with a developmental disability as well as for any other children. Within the community, primarily due to the lack of attention and advocacy for Asian-Americans with developmental disabilities, the resources for this population are limited, for instance, in terms of formal and informal social support or service programs. As a result, the limited resources would keep the families from making efficient and complete treatment plans. Lack of active advocacy for this population was also reported as responsible for the status quo.

* "Lack of resources and skills to care for the children within the family."
* "Inadequate formal and informal service program or support for Asian with developmental disabilities."
* "Lack of transportation."
* "Much needed services for these particular target groups."
* "Lack of active advocate for this group and client."

Communication Barriers due to the Language Differences

Communication difficulties due to language differences were another main source of the problems experienced by Asian-Americans with developmental disabilities. The Asian-American community service providers, as well as the mainstream service providers, also seem to experience difficulties when the service providers do not speak the clients' native language or dialect. Given that there are many different dialects in some Asian ethnic languages, some Asian-American community service agencies may not able to provide services to some clients when no service providers are available to speak the same dialect of the language spoken by the clients.

* "English barrier."
* "Language and cultural barriers;."
* "Lack of service/program providers that speak the clients' language."

Cultural Differences

Some respondents indicated that cultural differences in belief or value systems might be a factor which causes difficulties for Asian-Americans with developmental disabilities when utilizing mainstream social services. Racial/ethnic prejudices operating in the mainstream service delivery system might also discourage Asian-Americans from utilizing the resources available to them. In addition, some responses reflected that Asian-American values such as the importance of family privacy might work against those family members with developmental disabilities who might need outside help and support. One response suggested that having a family member with a developmental disability in the family might become "a family secret," which makes it harder for outside support systems to intervene with the family.

* "Cultural beliefs and racial prejudices."
* "Family reluctance to reveal the family problem and seek help."
* "Families is very shameful and secretive about the fact that there is a member with developmental disabilities in their own house. They are not open about discussing the issues and difficulties. However, with skillful approach they could be benefited a great deal."

Difficulties Common to Individuals with Developmental Disabilities and Specific to Asian-Americans

One response reflected that Asian-Americans have to deal with difficulties common to all individuals with developmental disabilities coupled with barriers created by their cultural/ethnic differences as Asian-Americans.

* "Probably the same as non-ethnic developmentally disabled individuals plus issues from ethnic/cultural differences."

D. Suggestions and Recommendations for Working Effectively with and Reaching Out to Asian-Americans with Developmental Disabilities

Need for Increasing Awareness of Developmental Disabilities Through Educational Programs

The major recommendation suggested by the respondents was that in order to increase the awareness of and the access to available resources, educational programs should be designed for various purposes both at the family level and the community level. These educational programs should include the information to increase the understanding about the nature of developmental disabilities and the types of care necessary for a specific developmental disability. Especially, any programs designed for Asian-Americans should take into account the values and belief systems unique to this population. It was recommended that when some of the cultural and family values conflict with the principles grounded in the mainstream health care system, focused individual or family counseling might be beneficial to ensure the optimal care of the family member with a developmental disability.

* "Lack of knowledge and access to available resources need more educational programs."
* "Educate and access them with much needed resources and services."
* "Different values and attitudes of the family toward the member with disability need both educational programs as well as individual/family counseling are deemed imperative."
* "Education not only for concerned families but the community as a whole to accept and have sympathy for the victims."

Need for Social Services Tailored to the Special Needs of Asian-Americans

Recognizing the importance of providing social services tailored to the special needs of Asian-Americans with developmental disabilities, primarily due to their immigration experiences and different cultural/ethnic backgrounds, some respondents provided concrete recommendations for needed social service programs. Recent immigrants with developmental disabilities might need vocational training along with an additional emphasis on increasing English proficiency for minimal survival in the new environment and society. In addition, in order to facilitate their adjustment to the new country, entertainment activities highlighting the assets of the majority culture could help them comfortably learn and relate to the mainstream cultural norms.

* "Survival English skill for vocational training."
* "Entertainment activities for adjusting to the new culture. "

Support groups available to the individuals with developmental disabilities as well as their families in their own Asian ethnic group could be beneficial. -- given that the cultural and language barriers among the group could be minimized, especially for those who have not acquired English proficiency. Since the acculturation level and English proficiency would vary among the group members, the support group could be a place where they could share their adjustment experiences and learn from others'. Additionally, one respondent suggested that the early identification and recognition of a person who could be regarded as a group leader by the members in such a group setting might help facilitate the cohesion of a group. This strategy would be based on the culturally appropriate observation of group dynamics and the importance

of hierarchy in interpersonal relationships and of collectivistic efforts toward group work in some Asian cultures.

* "Formation of support groups."
* "Family support group among same ethnic/cultural group."
* "Identify group leader among themselves so that they could identify with comfortable feelings."

Phase III: Interviews and Focus Group with Asian-Americans with Developmental Disabilities

Purpose of the Study

The primary goal of conducting individual interviews and focus groups with Asian-American families affected by developmental disabilities was to gain first-hand descriptions of providing care to the family member with a developmental disability. The main area of inquiry was barriers and difficulties experienced by this population in the process of gaining access to formal and informal resources and services available to them. The second domain of interest was social support and service programs needed by them. New approaches to this population in the mainstream and community service delivery can be developed based on their first-hand accounts of their experiences as the consumer of the services integrated with the service providers' professional suggestions to meet their special needs.

Procedure of the Study

The potential participants for individual interviews and focus groups were recruited by two main methods. First, the planning of focus groups and of individual interviews for the study of needs assessment of Asian-Americans with developmental disabilities was announced through the 14 major Asian-American ethnic newspapers in each Asian ethnic language. Any Asian-American individuals or family members affected by developmental disabilities were encouraged to contact the investigator of the present study and to contribute to the needs assessment of Asian-Americans with developmental disabilities.

The second method involved contacting 32 service providers who had indicated in the survey during the first phase of the project that they would be willing to help form a focus group with the Asian-American clients at their agency. A cover letter addressed to these service providers was mailed along with the fliers of invitation to focus group. This flier was developed to encourage the families of Asian-Americans with developmental disabilities to participate in a focus group and detailed the purpose of a focus group, the importance of their participation, the information about the date, time, and place that the focus group might be held (See Appendix 6). The service providers were requested to deliver the enclosed fliers to their Asian-American clients. The number of fliers enclosed was equivalent to the number of Asian-American clients previously reported by the mainstream service providers who were utilizing services at their agency.

The individual interviews and the focus group were conducted according to the structured interview format, which includes demographic and socioeconomic information about the interviewees, ratings of the needed service programs on a 5-point scale, and barriers encountered in the service delivery system and special needs for services and support (See Appendix 7). Less than an hour was spent on an individual interview and the focus group took about an hour and a half. Each participant received $20.00 as a token of appreciation.

Results and Findings

As the result of the recruitment of participants, three individual interviews were conducted and one focus group was formed. The interviewees included 1) a Filipino mother with a 3 year-old son with severe cerebral palsy; 2) an Asian-Indian mother with a 26 year-old daughter with moderate mental retardation; 3) an Asian-Indian mother with a 26 year-old son with mild mental retardation. The focus group was formed with the help of the community service provider working at one of the Korean-American community service agencies. The four Korean-American families involved in the focus group were receiving some form of services at the Korean-American Community Services for their child with a developmental disability. The participants in the focus group included the four Korean-American parents, the community service provider, and a facilitator: 1) a Korean-American father with a 21 year-old son with mental retardation; 2) a Korean-American father with a 10 year-old son with mental retardation; 3) a Korean-American father with a 2 year-old daughter with a heart problem; 4) a Korean-American mother with a 5 year-old son with autism; 5) a Korean-American community service provider working at the Korean-American Community Services; 6) a facilitator.

Findings from the Individual Interviews and the Focus Group

This section discusses the major issues emerging from the individual interviews and the focus group discussion.

1. Lack of information and knowledge on the special education, health care, and social delivery systems; Need for increasing awareness in the community of the educational and social service delivery system.

Lack of Awareness of and Misunderstanding about the Health Care and Educational Systems

The focus group discussion revealed that Korean-American parents with children with developmental disabilities and Korean-speaking service providers in the Korean-American community lack in information and knowledge of public financial assistance, treatment options, and special education programs for people with developmental disabilities in the mainstream society. It was pointed out that community service providers are not necessarily well aware of the resources and procedures practiced in the mainstream service delivery for this population unless they have had years of working experiences or education in these disabilities. Since knowledge about service delivery for people with developmental disabilities in the mainstream society is a specialized area, it is as unfamiliar to community service providers as to people in the community, although people in the Asian-American community are more likely to suffer from serious deficits in gaining access to resources. This strongly suggests the need for educating community service providers as well as people in the community regarding available mainstream services.

On the other hand, the familiarity of the health care systems practiced in the native country might cause recent Asian-American immigrants interference in learning the new system in the

U.S., creating confusion and misunderstanding about the underlying principles and specific procedures formally and informally operating in the mainstream health care system and related disciplines. For instance, one parent in the focus group reported that she unsuccessfully and wastefully searched for a special education school for her child. Since she was familiar with the separate school systems for normal children and children with disabilities practiced in the educational system of her native country, she incorrectly assumed the same practice exists in the U.S. educational system. Without the professional's guidance, she could not question the differences in special education systems between Korea and the U.S.

Need for Disseminating Information Regarding Treatment Options for Care

Those Asian-Americans who are unfamiliar with the mainstream educational and health care systems are more likely to be subject to numerous trial and error experiences by going through unnecessary procedures prior to reaching the most appropriate treatment and educational plan for the child's needs. If these parents were guided by some professional assistance in arranging effective treatment plans from the time of their first learning of a disability in the child, they could have avoided wasting time and energy trying out ineffective approaches. Emotional costs are also high due to the uncertainty of not knowing how to care for the child and what is most effective. Feelings of helplessness and lack of control over their situations might be unduly prolonged and in some cases, prevent effective treatment altogether.

In order to prevent unnecessary emotional and practical costs, education about developmental disabilities for people in the Asian-American community should be initiated through the dissemination of the information, especially about the educational and school systems, health care system, and social delivery systems in the mainstream society. "Newsletters" targeted to Asian-American families with individuals with developmental disabilities were suggested by the focus group to be helpful in widely disseminating information covering a broad range of topics: the nature of developmental disabilities, treatment options, public financial assistance, service agencies hospitals within their geographic proximity, and so on.

2. Problems in communication due to language differences for both the children with developmental disabilities and their families; Need for increasing the number of bilingual staff in school and social service delivery systems.

Need for Bilingual Staff in the Service Delivery System for Developmental Disabilities

Many problems arise due to the primary language differences between the mainstream service providers and Asian-American clients. One parent in the focus group expressed the deepest concern for his son's language development. His 10 year-old son with mental retardation is exposed to the three different languages: English spoken at school, Korean spoken at home, and Spanish spoken by a Mexican baby-sitter. He was concerned that the exposure to too many different languages might unduly delay and adversely affect his son's communication skills and mental ability. The parents in the focus group generally expressed their preference for the Korean language as the primary language to be spoken at home and wished that their children could be supervised by bilingual Korean-speaking teachers, social workers, service providers, and baby-

sitters. They also expressed their need for bilingual Korean-American social workers in the field who could assist their children for adequate bilingual language development.

Need for Professional Speech Therapy for in Asian Ethnic Languages

In addition, some parents expressed their desire for gaining access to speech therapy for their children in the Korean language. One parent reported her unsuccessful attempts to locate a professional who could provide speech therapy for her son in the Korean language. The community service provider participant in the focus group added that she herself is a licensed speech therapist in the Korean language certified in Korea. However, she indicated that her license is not approved by the U.S. authorities. It was argued by the participants that for the early-aged Asian-American children who begin their early development of communication and language skills, speech therapy should de devoted to the primary language spoken with their parents. These parents expressed the need for approving the practice of speech therapy in diverse Asian ethnic languages if the therapists were certified in their language by their native country.

Need for Testing Instruments and Bilingual Staff to Administer Culturally-Appropriate Assessment of Mental Ability for Asian-Americans with Developmental Disabilities

It appears extremely difficult for the mainstream professionals to administer clinical testing to assess mental ability of the Asian-American children in early childhood, especially of those under the age of three. The majority of testing instruments used in evaluating intelligence and mental functioning require basic English vocabulary and comprehension skills and may not be appropriate for testing Asian-American children whose primary language, spoken with their primary care takers, is their Asian native language. The accurate clinical assessment of a suspected developmental disability for Asian-American children and its severity seems challenging to the mainstream English-speaking clinicians and the process of obtaining a final diagnosis of a disability may be prolonged. One parent in the focus group shared her past experience of going through additional testing and examinations for a long period of time before the final diagnosis of autism was reached in her son's case. No testing materials for measuring intellectual functioning in Asian ethnic languages seem available in the mainstream service system and the number of bilingual staff able to adequately administer mental testing in diverse Asian languages seems scarce.

Need for Bilingual Translators and Need for Training Translators in the Vocabulary of Specialized Technical Terms Used in Developmental Disabilities and Special Education

Translation service was identified as one of the most needed types of assistance that should be conveniently arranged in case of need and immediately available in case of emergency. The participants of the focus group expressed the difficulties locating bilingual persons who are fluent enough both in English and their native language to help them accurately communicate with the mainstream service providers.

In addition to locating bilingual translators, additional problems emerge when the translators are not familiar with the vocabulary used in the field of developmental disabilities and

are unable to understand the terminology regarding the specialized medical treatment. The participants reported the risks and dangers involved in employing ordinary persons for translation in highly complicated medical situations. The translators' lack of vocabulary in the field of developmental disabilities seems to frustrate both mainstream service providers and Asian-American clients. It was desired by the participants that they could have a resource from which they can reliably request translation services provided by bilingual personnel competent in translating in their native language and well equipped with the specialized vocabulary base in the field of developmental disabilities.

3. The importance of the function Asian-American pediatricians in private practice; Need for educating Asian-American pediatricians in the service delivery for people with developmental disabilities

Importance of the potential function of Asian-American medical professionals in private practice whose major clientele is Asian-Americans

Korean-American parents seem more likely to go to see Korean-speaking Korean-American pediatricians or doctors in private practice in the community when they notice some problems with their children's health because of easy communication and cultural understanding. However, as reported by the three participants in the focus group, there seems to exist some mistrust toward these medical doctors in the community. For instance, one father in the focus group reported that the diagnosis of epilepsy for his son was delayed for two years because his son's pediatrician did not correctly detect the problem. Two other participants also added some of their negative experiences with other Korean-American medical doctors in private practice in the community. They attributed some of these doctors' blunders to "the lack of the doctors' care for each patient, " "the refusal to refer their patients to other doctors when their specialty is not sufficient," "a single desire for making profits," "lack of time," and "lack of doctors' knowledge of the mainstream health care system for people with developmental disabilities." The participants expressed suspicion and mistrust in these doctors' medical competence and credibility because of the doctors' observed inability to accurately make a diagnosis of the disability and to provide information and resources for the future course of treatment. Mistrust toward the community medical doctors seems to be made worse because the participants did not want to get involved in any legal affairs resulting from malpractice suits, which might, they think, damage their family name and lead to a loss of face.

On the contrary, the father of the child with epilepsy who reported the negative experience with one Korean-American pediatrician at the initial stage of diagnosis added his positive experience with a different Korean-American pediatrician (after he changed his son's pediatrician). The new doctor was a great deal of help in applying for the public financial assistance and gaining access to an appropriate facility in the mainstream service system. This case demonstrates some ambivalent feelings shared by Korean-Americans primarily caused by a) their reliance on the community doctors, in spite of the mistrust toward these doctors, due to their limited resources and language barriers keeping them from utilizing the mainstream medical services and b) their appreciation of the potential helpfulness of well-informed and educated

community doctors being capable of making referrals to the mainstream service delivery system for their clients with developmental disabilities.

Need for Educating Community Medical Doctors and Professionals in Private Practice

In order to ensure optimal and complete preventive care and intervention for Asian-Americans with developmental disabilities, community pediatricians and doctors in the community whose major clientele is Asian-Americans need to be further educated in the specialized knowledge of developmental disabilities. Information dissemination, workshops, and seminars might be helpful, comprehensively covering a wide range of issues that these professionals should be aware of when having Asian-American clients with a suspected developmental disability (e.g., the differential diagnosis for developmental disabilities, the mainstream health care system for people with developmental disabilities in the U.S., referral sources and systems, formal and informal resources available for people with developmental disabilities and their families in the mainstream society and in the community, etc.).

Additionally, it was suggested that a centralized referral system for Asian-Americans with developmental disabilities might be a reliable source for the community doctors who are not well equipped with information and social service provisions for people with developmental disabilities in mainstream society. If these doctors are not able to provide complete guidance for their Asian-American clients with developmental disabilities, they should refer these clients to this centralized referral system which would responsibly provide complete case management services. Potentially, community medical professionals could play a significant role in connecting Asian-Americans with developmental disabilities and the mainstream service delivery system.

4. Need for designing culturally-sensitive social service programs for Asian-Americans with developmental disabilities

Being a Minority Client Population in the Mainstream Service Delivery System

One participant in the focus group reported difficulty getting his son involved in a group activity with Caucasian children with developmental disabilities at the service agency. He felt that his son was somehow isolated by other children because they might think that his son looked "different" from them and did not understand their language. Due to the language barriers and ethnic differences, some Asian-Americans with developmental disabilities as a minority client population utilizing services in the mainstream social service agencies might experience feelings of isolation and, as a result, receive less support from their peers and service providers than those from the majority culture. Consequently, Asian-American families having a family member with a developmental disability may not be able to fully utilize external social services support, care, and supervision even if these resources are available. These families are more likely to be required to rely on their internal family resources to attend to the needs of their family member with developmental disabilities due to the various barriers keeping them from fully and independently utilizing external resources.

Need for Collective Efforts to Strengthen Ties among Asian-Americans with Developmental Disabilities

Due to some disadvantageous consequences caused by being a minority client population utilizing services in the mainstream society, it was recommended by the focus group that Asian-American families themselves should locate and reach out to other Asian-American families affected by developmental disabilities so that they could be resourceful to one another. As a result of these efforts, a directory for Asian-Americans with developmental disabilities should be developed which includes identities of the Asian-American individuals with developmental disabilities and of primary care takers, the type of disability, ethnicity, gender and willingness to share their personal experiences related to these disabilities. It should be widely circulated in the Asian-American communities to reach out people who might gain benefits from the information provided by the individuals listed in the directory. In addition to the practical benefits, these collective efforts to strengthen ties among Asian-Americans with developmental disabilities would give them a stronger sense of control and empowerment over their unique situations as well as a sense of belongingness to the community.

Need for Social Support Programs Designed for Asian-Americans with Developmental Disabilities

Some participants expressed their wish for having formal and informal social support groups for Asian-American individuals with developmental disabilities and for the families affected by these disabilities. Due to the diverse Asian ethnic language differences within the Asian-American community, the primary language or dialect spoken by the family may have to be a determining factor in designing separate social support groups in each ethnic community. In addition, the participants in the focus group expressed their willingness to work with other Asian ethnic groups identifying their common feelings about the cultural similarities among different Asian-American ethnic groups if the language barrier can be minimized and competent bilingual service providers are available.

The focus group addressed why a few already existing formal or informal support groups for Korean-Americans with developmental disabilities in the community have not been successful. One of the reasons speculated was the parents' lack of time after work to participate in these group activities because most Korean-American parents tend to work until late. It seems hard for them to find a baby-sitter to supervise their children when they have to leave home. The second reason was that most of the existing support groups are operated by private or missionary organizations with their own goals and interests preset for the groups. It was observed that unless the families' interests match with the sponsors', they are not likely to participate in those social support group activities. The third reason was that these support programs are not broadly publicized and put minimal effort into reaching out to those in need in the community. The group members themselves reportedly value keeping confidentiality among their internal members which then might appear too private and exclusive to outside people who potentially might want to join the group or to contact a member for help.

Culturally-Appropriate Social Service Programs and Effective Outreach Strategies

The community service provider participant in the focus group, based on her experiences working with Korean-Americans in the community, strongly pointed out that social service programs and outreach strategies should be carefully designed and implemented in accordance with the unique needs and preferences of Korean-American or Asian-American families in a culturally appropriate manner. She stressed that social service programs remodeled after the programs for Caucasian middle-class population may not be successful with Asian-Americans. She suggested that a needs assessment for the target group should be systematically implemented before the initiation of any social service programs. In the process of a needs assessment, she recommended that service providers should make a direct personal contact with each potential recipient of a future program, assessing their unique needs and communicating with them about its potential helpfulness. As the result of an active needs assessment, the potential recipients of the benefits of the program could have an opportunity to engage in the process of designing the program and thus gain maximum benefits from the program once it was implemented. In addition, the professionals' individual contacts and exchange of thoughts with them during the program design process might break down any possible mistrust toward the social service providers and make it easier for client families to commit themselves to participating in social service programs in the future.

Individualized Social Services Tailored to the Unique Needs of Each Individual and Family

Most participants in the focus group expressed that sometimes they found it less effective to participate in seminars and workshops aimed at providing general information about specific issues regarding developmental disabilities. Instead, they preferred one-on-one individualized services, directly and specifically focusing on their particular needs. In addition to the lack of information on the resources available, it appears that another problem arises when parents or other caregivers do not know how to apply the acquired information to their unique circumstances. There appeared to be a gap between the acquisition of information and the application of that knowledge to their specific case. These parents seemed to feel inadequate and overwhelmed by the need to maintain comprehensive management on multiple dimensions in caring for the family member with a developmental disability. They expressed a strong need for having a reliable case manager who would continuously and regularly provide individualized case management services with complete and comprehensive medical, psychological, and financial management for their family member with a specific developmental disability. It was also suggested that highly individualized case management services such as home-visit check-ups and follow-ups by case management personnel would be of great help given the limited time and flexibility available to these families. The home-visit service mode was also suggested by the focus group for couple's conflict resolution and family counseling.

Need for a Centralized Referral System

It was suggested that there should be a centralized referral or case management system which would serve to meet the multi-dimensional needs of Asian-Americans with developmental disabilities. This proposed centralized system would perform several functions fulfilled by a

central agency that is equipped with personnel and resources fitted to the specific needs of and the diverse cultural/ethnic backgrounds, language differences, and socio-historical backgrounds of Asian-Americans with developmental disabilities. First, the agency would perform its major function as a central clearinghouse, mainly disseminating practical and educational information to families of people with developmental disabilities in the diverse Asian-American communities. The information should cover a wide range of topics: materials for better understanding the nature of developmental disabilities, treatment options and provisions, special education, public financial assistance and so on. This function could be achieved by means of brochures, regularly published newsletters, seminars and workshops, and direct formal and informal contacts with people in need. The materials should be translated into diverse Asian ethnic languages and be disseminated to major Asian-American communities, available to any Asian-American individuals who want to seek the information.

Another proposed function of the central agency was that it should serve as a centralized referral system to Asian-Americans with developmental disabilities, the service providers in the mainstream service delivery system, and professionals of the related disciplines in the community. This referral system would function as central referral source coordinating various types of information to assist all the parties involved in the service delivery for Asian-Americans with developmental disabilities. Services desired by the focus group participants were locating a service agency which best matches with their financial situation, ethnic/linguistic background, socioeconomic status, geographic location and so on. Services would also include providing direct translation services or arranging translators for the clients within geographic proximity.

IV. Conclusions and Recommendations for the Future

In this section, important thematic findings emerging from the survey of the mainstream service providers, the survey of the community service providers, and the interviews and the focus group are discussed in conjunction with corresponding actions to be taken to address those issues.

Understanding Prevalence Rates and the Need for Research in Demographic Characteristics among Unserved Asian-Americans with Developmental Disabilities

The estimated number of Asian-Americans in the Chicago area who might have mental retardation is 2,277 and the number of Asian-Americans with developmental disabilities might be larger if other types of developmental disabilities are included. The total numbers of Asian-American clients reported by mainstream service providers and by the community service providers as receiving some forms of services at formal agencies was 94 and 23, respectively. Even allowing for the possibility that not all agencies could be contacted and the response rate to the contacted agencies was 40%, the discrepancy between the estimated prevalence of mental retardation and the number of persons with mental retardation being served is striking. It is not clear if these cases were simply not reported by the survey response or, possibly, were not utilizing any forms of formal services at the time of the survey. More research is needed to understand this gap and to determine the size of the population of Asian-Americans with developmental disabilities who are unserved by the mainstream and community service agencies. Research methodologies need to be applied creatively to identify the demographic characteristics and special needs of this potentially unserved population.

Understanding Service Utilization Patterns and the Need for Strengthening Cultural Sensitivity of Mainstream and Community Service Agencies

While the diverse Asian-American ethnic people with various types of developmental disabilities utilize a wide range of services both at the mainstream and community service agencies, these two systems of service agencies appear to serve different needs of this population (See Table 5). First, the mean ages of the Asian-American clients utilizing services at the mainstream agencies and those at the community service agencies were 16 and 24 respectively. The community service agencies seem to have an older and a wider age range of client population than mainstream service agencies. Second, the more severely disabled clients were served by mainstream service agencies, whereas approximately half of the client population at the community service agencies (43%) consisted of persons with moderate disabilities. In addition, families seem to utilize different types of services from mainstream and community service agencies. While developmental and vocational training were most frequently reported services utilized by Asian-American clients at mainstream agencies, direct medical treatment types of services were also likely to be utilized within mainstream agencies. On the other hand, Asian-American clients with developmental disabilities appear to utilize indirect and less formal forms of treatment such as information seeking, referral, translation services, and legal services from the community service agencies.

Table 5. *Comparative Asian-American Client Characteristics between at Mainstream and Community Service Agencies*

	Mainstream Service Agencies	Community Service Agencies
Mean age	16	24
Age Range	1-38	3-50
Severity	Severe (31%) Moderate (21%) Mild (22%)	Severe (26%) Moderate (43%) Mild (17%)
Services Used	Developmental training (26%) Vocational training (26%) Nursing/Habitation (12%) Academic Education (12%) Recreation (9%) Respite (5%) Case Management (2%) Family Support (2 %) Physical Therapy (2 %) Early Intervention Program (1%) Speech Therapy (1%)	Information/referral (35%) Family counseling (22%) Vocational Training (9%) Counseling (13%) Translation for Psychiatrists(9%) Homemaker Services (4%) Arranging for Community Care (4%) Arranging for Legal Services (4%) Entitlement (4%)

Therefore, as one can see from the Table 5, these two systems of service delivery to Asian-Americans with developmental disabilities seem to serve different needs for different types of clients: The mainstream service delivery system provides more direct treatment services to younger Asian-Americans with more severe developmental disability whereas the community service delivery system provides indirect and complementary services to relatively older Asian-Americans with mild developmental disability. These differential functions need to be further explored and should be strengthened to meet the wide range of needs for Asian-Americans with developmental disabilities.

Understanding Language Barriers and the Need for Language-appropriate Service Delivery

Communication difficulties due to language differences have been unanimously pointed out as the most significant barrier when Asian-American clients with limited English seek services in the mainstream service delivery system and when the English-speaking mainstream service providers attempt to serve them. a) There is a need for increasing the number of bilingual staff, in diverse Asian ethnic languages, in the service delivery system for Asian-Americans with developmental disabilities and their families when they have limited English proficiency. It is also critical to train bilingual clinicians and medical doctors who could competently evaluate, at initial diagnosis, the mental and intellectual functioning of the limited English-speaking Asian-Americans given the absence of valid testing instruments for this population; b) Formal translation services, available

and reliable, need to be coordinated to assist both Asian-Americans and the mainstream service providers in case of need and emergency. Translators are needed to be trained, prior to providing services, in the specialized medical and diagnostic vocabulary used in the field of developmental disabilities and in the administration of the health care and educational systems for people with developmental disabilities; c) There is a need for considering professional training and certifying of speech therapists in Asian ethnic languages because the focus group discussion revealed great difficulty in obtaining these services by many families; d) An alternative approach to overcoming language barriers might include using service delivery that de-emphasizes the use of language as a communication mode, i.e., play therapy.

Understanding the Socio-cultural Characteristics of Asian-Americans with Developmental Disabilities and the Need for Educating Mainstream Service Providers to Increase Culturally Relevant Service Delivery

The unique socio-cultural characteristics of Asian-American families need to be considered at every stage of service delivery. a) Their different views on the etiology of and treatment for developmental disabilities need to be understood by the mainstream service providers and incorporated into the service delivery processes. Culturally appropriate explanatory systems for developmental disabilities should be developed and the helpfulness of the use of culture-specific treatments should be understood; b) The cultural importance of privacy in family life, familial responsibilities, intergenerational support and expectations, and gender-related issues such as sex-role differences need to be understood and appreciated in the interactive process of treatment. Mainstream service providers need to be trained in increasing multi-cultural awareness and sensitivity and learning ways of dealing with cultural differences between them and their clients; c) Asian-Americans with developmental disabilities are an ethnic/cultural minority client population in the mainstream service delivery system, which might increase a sense of isolation and limit the usefulness of the formal services. There is a need for designing service programs addressing this status of Asian-Americans with developmental disabilities by developing social support programs for this population and helping them strengthen the formal and informal ties among them.

Lack of Resources and Knowledge of the Health Care, Medical Service Delivery, and Educational System and the Need for Outreach and Education in the Community

It is clear from multiple sources that Asian-Americans are lacking in knowledge of medical, health care, educational, and social service delivery systems for individuals with developmental disabilities in mainstream society. Lack of resources in their formal and informal network systems further leads to confusion, misunderstanding, and deficits in information about various systems involved in the care of a person with a developmental disability. a) There is an immediate need for education and information dissemination regarding the nature of developmental disabilities, health care systems, treatment options, educational and school systems, service delivery systems, service agencies within the geographic proximity to their communities and, particularly, Asian-Americans affected by disabilities as a target group. This can be achieved by means of brochures, newsletters, workshops, and or other modes of educational programs; b) Organizing community-based resources could help Asian-Americans with developmental

disabilities strengthen their sense of control and empowerment. Developing a directory for Asian-Americans with developmental disabilities would be helpful creating shared experiences and allow them to become more resourceful among themselves. A resource book should be developed to help them gain information about mainstream and community service agencies, bilingual/bicultural Asian-American professionals in the related disciplines, translation and transportation services, and other information necessary to assure comprehensive care; c) There also is a need for educating community doctors and professionals working in the related disciplines who are most likely to be contacted by Asian-Americans when there is an initial concern about a possible disability. The professionals need to be equipped with information regarding service provision for people with developmental disabilities to help their clients' families make effective treatment plans and to arrange referrals; d) Outreach and advocacy activities should be pursued, seeking out especially those who are unserved. Culturally effective outreach strategies need to be developed highlighting the importance of direct contact with each individual.

Understanding the Special and Individual Needs of Asian-Americans with Developmental Disabilities and the Need for Providing Comprehensive Services

Even though Asian-Americans affected by developmental disabilities could be regarded as a homogeneous group, to some degree, on the basis of their Asian origin and a disability condition common to all of them, in actuality, they are a heterogeneous group of people in terms of their diverse ethnic/cultural origins, native languages, gender, age, type and severity of developmental disability, socioeconomic status, acculturation level, English proficiency, and other characteristics. Thus, any services provided to an Asian-American individual with a developmental disability should take into account these attributes of individual differences as well as the universal needs common to all populations. a) Outreach activities and service programs need be individually and differentially designed and implemented to meet unique needs of each Asian-American individual and family affected by a developmental disability. Case management services for each individual or family that would provide a wide range of comprehensive medical, psychological, and financial management services has great potential for being most helpful.; b) In order to efficiently meet the unique and multiple needs of Asian-Americans, a centralized referral and case management system is strongly recommended by both service providers and Asian-American clients. An agency designated as a centralized referral system could perform multiple roles: a clearinghouse disseminating information and educating the communities; a referral system connecting mainstream service agencies, community service providers, and Asian-American clients for a best match of needs and services, as well as coordinating translation and transportation services.

BIBLIOGRAPHY

Beirne-Smith, M., Patton, J., & Ittenbach, R. (1994). Mental retardation (4th ed.). New York, NY: Macmillan College Publishing Company.

Casas, J.M. (1985). The status of racial- and ethnic-minority counseling. In P. Pederson (Eds.), Handbook of cross-cultural counseling and therapy (pp. 267-274). Westport, CT: Greenwood.

Chan, D.C. (1976). Asian-American handicapped people: An area of concern. Journal of Rehabilitation, 42, 14-16, 49.

Chan, S. (1981). Serving Pacific Asians with developmental disabilities. Journal of the Asian-American Psychological association, 6, 3-8.

Cheung, F.K., & Snowden, L.R. (1990). Community mental health and ethnic minority population. Community Mental Health Journal, 26, 277-291

Crystal, D. (1989). Asian-Americans and the myth of the model minority. Social Casework: The Journal of Contemporary Social Work, 70, 405-413.

Flaskerud, J.H. (1986). The effects of culture-compatible intervention on the utilization of mental health services by minority clients. Community Mental Health Journal, 22, 127-141.

Gorelick, M. (1981). An invitation to speak about mental retardation to the People's Republic of China. Mental Retardation, 19, 183-186.

1994-1995 Human Care Services Directory of Metropolitan Chicago.

Lin, T. (1983). Psychiatry and Chinese culture. Western Journal of Medicine, 139, 868-874.

Malekoff, A., Johnson, H., & Klappersack, B. (Eds.) (1995). Ethnic Chicago: Multiple Portrait. Grand Rapids, MI: William B. Eerdmans Publishing Company.

O'Sullivan, M.J., Peterson, P.D., Cox, G.B., & Kirkeby, J. (1989). Ethnic populations: Community mental health services ten years later. American Journal of Community Psychology, 17, 17-30.

Polloway, E.A., Epstein, M.H., Patton, J.R., Cullin, D., & Luebke, J. (1986). Demographic, social and behavioral characteristics of students with educable mental retardation. Education and Training of the Mentally Retarded, 21, 27-34

Ryan, A.S., & Smith, M.J. (1989). Parental reactions to developmental disabilities in Chinese American families. Child and Adolescent Social Work, 6, 283-299.

Smith, M.J., & Ryan, A.S. (1987). Chinese-American families of children with developmental disabilities: An exploratory study of reactions to service providers. Mental Retardation, 25, 345-350.

Sue, D.W. (1977). Counseling the culturally different: A conceptual analysis. Personnel & Guidance Journal, 55, 422-425.

Sue, S. (1988). Psychotherapeutic services for ethnic minorities: Two decades of research findings. American Psychologist, 43, 301-308.

Sue, S., & McKinney, H. (1975). Asian Americans in the community health care system. American Journal of Orthopsychiatry, 41, 111-118.

Sue, D.W., & Sue, D. (1990). Counseling the culturally different (2nd ed.). New York, NY: John Wiley & Sons, Inc.

Sue, S., & Zane, N. (1987). The role of culture and cultural techniques in psychotherapy. American Psychologist, 42, 37-45.

Appendix 1

Asian Human Services of Chicago, Inc.

4753 N. Broadway Ave., • Suite 632, Chicago, Illinois 60640 • (312) 728-2235 • Fax (312) 728-4751

May 31, 1995

EXECUTIVE BOARD

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ABHA PANDYA

Director
Masjid Al-Amin
3702 W 11th Ave.
Gary, Indiana 46404

Dear Sir:

Asian Human Services of Chicago is pleased to announce the commencement of a one year study to identify specific needs and barriers to service for people with developmental disabilities in the Pan Asian community. Under a grant from the Illinois Planning Council on Developmental Disabilities, AHS intends to identify people with disabilities who are unserved or underserved within the Chicagoland area.

The State of Illinois defines developmental disabilities as any disability which is attributable to mental retardation, cerebral palsy, epilepsy or autism. Such a disability must originate before the age of 18 and constitutes a substantial, indefinite barrier to normal functioning. Since the 1970's state, federal and local agencies have developed community-based support programs to assist individuals with these disabilities and their families. These services include home care, health care, Social Security disability payments, educational training, job placement, and transportation supports.

Through this study, AHS intends to make sure that these essential services will become more accessible to affected individuals and their families in the Asian community. The study will not only account for people with disabilities who were unrepresented in previous assessments, but also identify gaps in services and the cultural and language barriers to service provision. The overall objective will be to help social service agencies and service providers to develop plans for support services which are culturally relevant and to train professionals from outside the community to understand the social customs and special needs of people from different ethnic groups in the Pan Asian community.

Mr. Nayan Shah, Ph.D., will be coordinating the launch of the study and will in the coming weeks be contacting local community organizations, schools, social service agencies, physicians and media to gather information about people with developmental disabilities in the Pan Asian community.

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Please feel free to contact Dr. Shah if you have any information or questions about people with developmental disabilities in your community. He can be reached at (312) 271-3883.

We invite your assistance in helping AHS improve the outreach and services for individuals with developmental disabilities. This study will have a wide distribution throughout Illinois and is an outstanding opportunity to identify barriers and to transform the service provisions for the Pan Asian community.

We look forward to working with affected individuals, families and communities for the successful completion of this vital project.

Sincerely,

Abha Pandya

Abha Pandya
Executive Director

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Appendix 2

Asian Human Services of Chicago, Inc.

4753 N. Broadway Ave., • Suite 632, Chicago, Illinois 60640 • (312) 728-2285 • Fax (312) 728-4751

October 27, 1995

David Bauer, Director
Glen Ellyn Clinic
454 Pennsylvania Ave.
Glen Ellyn, IL 60137

Dear Mr. David Bauer:

Under a grant from the Illinois Planning Council on Developmental Disabilities, Asian Human Services of Chicago is conducting a needs-assessment for people with developmental disabilities in the Asian-American community. This needs-assessment project aims to understand the prevalence of these disabilities, the current status of service utilization, difficulties and barriers encountered by these individuals and their families, and special needs for services. The results of this project will help develop programs tailored to the special needs of the Asian-American community and offer expanded services to those who currently are under utilizing them.

Enclosed is the survey questionnaire which was developed as a part of this process to estimate the number of Asian-Americans with developmental disabilities who are currently utilizing services. Unfortunately, there is no information available in the literature on the current prevalence of developmental disabilities in Asian-American community. That is why your participation in this survey is critically important to us because the information you provide will serve to estimate the current prevalence rate of developmental disabilities among Asian-Americans.

We would greatly appreciate it if you would be willing to participate in this survey process. The questionnaire is designed to be answered by someone at your agency who is able to provide specific information about the Asian-American clients with developmental disabilities including the type of disability, ethnicity, gender, and so on. The person who has some direct experiences working with these clients might be suited for answering the questionnaire. Please take a few minutes reading the questionnaire and transfer it along with the enclosed letter to someone who provides services to or has direct contact with these clients at your agency so that he or she could respond to the specific questions asked.

We understand that your time is valuable and that you have a busy schedule. However, without your assistance, this project is not possible. Your participation enables us to identify how many people are affected by developmental disabilities and to understand difficulties and problems distinct to them and their special needs for services. The results of this project will help to develop culturally-suited service programs for the individuals with these disabilities and their families in the Asian-American community. We will greatly appreciate it if you would take time to forward the questionnaire for completion and have it returned in three weeks, approximately by November 21. Please feel free to contact us if you have any questions or information relevant to this project. Thank you in advance for your interest and participation in this project.

Sincerely,

Keum Choi
Keum Choi, M.S.
- Primary Investigator

Martha Ellen Wynne
Martha Ellen Wynne, Ph.D.
Consultant

Abha Pandya
Abha Pandya
Executive Director

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Asian Human Services of Chicago, Inc.
4753 N. Broadway Ave., · Suite 832, Chicago, Illinois 60640 · (312) 728-2285 · Fax (312) 728-4751

Survey of Asian-Americans with Developmental Disabilities

Dear Survey Participant:

Your director has given this questionnaire to you for completion. Attached is the survey questionnaire which was developed to estimate the number of Asian-Americans with developmental disabilities who are currently utilizing services and to understand their special difficulties and needs for support and services. We need your help to accomplish this since no information is available in the current literature on the prevalence of developmental disabilities in Asian-American community. This is why your participation in this survey is critically important to us because the information you provide will serve to estimate the current prevalence rate of developmental disabilities among Asian-Americans.

We would greatly appreciate it if you would be willing to take some time to fill it out and send it back to us by November 21, 1995, with the attached self-addressed envelope. We understand that your time is valuable and that you have a busy schedule. However, without your assistance, this project is not possible. Your participation enables us to identify how many people are affected by developmental disabilities and to understand difficulties and problems particular to them and their special needs for services. The results of this project will help to develop culturally-suited service programs for the individuals with these disabilities and their families in the Asian-American community. Thank you in advance for your interest and participation in this project.

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Survey of Asian-Americans with Developmental Disabilities

Name of Your Agency: _____
Phone Number of Your Agency: (_____) _____
Address of Your Agency: _____
_____
_____

Name of Person Completing Survey: _____
Your Position or the Nature of Services You Provide:
_____

I. The State of Illinois defines developmental disabilities as any disability which is attributable to mental retardation, cerebral palsy, epilepsy or autism. Does you agency provide services specific to those with developmental disabilities? Please check one.

Yes _____ No _____

If your agency provides services to the developmentally disabled, we would like to know more about the Asian-American clients at your agency.

1. Asian-Americans are broadly defined as those whose families are from China, Taiwan, Korea, Japan, Philippine, India, Pakistan, Thailand, Hmong, Lao, Vietnam, Indonesia, Malaysia, Hong Kong and so on. Does your agency have Asian-American clients with developmental disabilities who are currently utilizing services at your agency? Please check one.

Yes _____ No _____

1a) If your answer was Yes, how many Asian-American clients are currently receiving services from your agency. Please indicate either the estimate or the actual number which is available to you.

Number of Asian-Americans receiving services at your facility: _____
The above number is _____ actual
_____ estimated
(please check one)

2. Provided on the next page is a guideline for filling out some non-confidential information we need to know about Asian-American clients. Following the example provided, please indicate specific information regarding Asian-American clients who are currently utilizing services at your agency. Fill out as much as information available to you for each client. (Please use the back side if additional space is necessary). Confidentiality of the clients is secured. It is not necessary to provide the clients' name. Please refer to the instruction section before attempting to complete the form.

We are planning to have focus group interview meetings with some Asian-Americans with developmental disabilities and their families in order to gain some understanding about their spacial needs for support and service. The group consists of 3 or 4 families with a developmentally disabled member and requires approximately an hour participation. The participating families are provided with $20.00 as the token of appreciation for their sharing. Would you be willing to forward this information to families of your clients whom you might be willing to participate in a focus group?

Yes _____ No _____

If yes, you will be contacted regarding planning of focus groups.

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Client Report Form

CLIENT #	AGE OF CLIENT	GENDER OF CLIENT	ETHNICITY OF CLIENT	TYPE OF DISABILITY	SEVERITY OF DISABILITY	SERVICES RENDERED
Instruction		f: female m: male	Chinese Taiwanese Korean Japanese Filipinos Indian Pakistanian Thai Hmong, Lao Vietnamese Indonesian Malaysian other (specify)	mr: mental retardation cp: cerebral palsy a: autism e: epilepsy other (specify)	IQ mild: 50-70 moderate: 30-50 severe: below 30	describe the services rendered to the client
Example:	*14*	*m*	*Chinese*	*mr*	*moderate*	*vocational training*
Client #1						
Client #2						
Client #3						
Client #4						
Client #5						
Client #6						
Client #7						
Client #8						

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II. Based on your past and current experiences working with the Asian-Americans with developmental disabilities and their families, have you or your agency ever felt that there are some difficulties and issues particular to working with Asian-Americans?

Yes _____ No _____

If the answer was Yes, please describe some of the difficulties you have experienced when working with them.

_____
_____
_____
_____
_____
_____
_____

III. Have you noticed that Asian-Americans with developmental disabilities and the families themselves have some difficulties unique to Asian-Americans, possibly due to their cultural/ethnic backgrounds or language differences, in the process of utilizing the services at your agency?

Yes _____ No _____

If the answer was Yes, please describe some difficulties that Asian-American clients and their families might experience when utilizing professional services at your agency.

_____
_____
_____
_____
_____
_____
_____
_____

IV. What kinds of issues do you think should be considered when working with Asian-American clients with developmental disabilities and their families? Please feel free to indicate any suggestions or recommendations for more effectively working with and reaching out them.

_____
_____
_____
_____
_____
_____
_____
_____
_____

Thank You Very Much for Your Interest and Participation in This Survey.

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Appendix 3

SERVICE AGENCIES WHICH CURRENTLY HAVE ASIAN-AMERICAN (AA) CLIENTS (WINTER 1995)

Respondents (Name/Position) Address/Phone #	# of actual/estimated AA clients Help for Focus Group	Clients Characteristics
1.ID- (01) Valee L. Salone, Executive Director NLA Comprehensive Center 1808 South State Chicago, IL 60616 312) 949-1808	actual 1 yes	
2. (02) Carol Montgomery-Fate, Social Worker United Cerebral Palsy Assoc. of Greater Chicago 155 N Wacker Drive Suite 315 Chicago, IL 60606 312) 368-0380	actual 2 yes	
3. (03) Donna Ree, Director of Quality Assuarance McKinley, Ada S-Community Services 725 S. Wells Chicago, IL 60607 312) 554-0600	actual 3 no	
4. (04) Robert Okazaki, Executive Director Avenues to Independence 3Northwest Suburban Aid for the Retarded 1841 Busse Highway Des Plaines, IL 60016 708)299-9720	actual 5 yes	
5. (05) Janice H. Murphy, Director of Community Services Countryside Association Countryside Center Community Services and Lapeside Center 21154 W. Shirley Rd. Palatine, IL 60074 708) 438-8855	actual 6 yes (would forward to families)	
6. (06) Wayne Pearce, Principal KREJCI Academy 140 N. Wright St. Naperville, IL 60540 708) 355-6870	actual 1 no	
7. (07) Gail Daish, Manager Intake, Evaluation and Assessment Victor C. Newman 3990 W. Barry Suite #110	actual 3 estimated 9 yes	

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312) 282-9404

8 (08)
Peggy Newmec, Parent Support
National Association for Down Syndrome
P.O. Box 4542
Oak Brook, IL 60522
708) 325-9112

estimated 10
no

9 (09)
Deb Darzinskis
Little Friends, Inc.
140 N. Wright St.
Naperville, IL 60540
708) 985-1125

actual 1
n/a

10. (10)
Dorothy Hough, Executive Director
Gateway to Learning
4925 N. Lincoln Ave.
Chicago, IL 60625
312) 784-3200

actual 3
yes

11. (11)
Pat O'Brien,
Vocational Training & Community Living Services
Happiday Centers
1005 West Endave
Chicago Hts., IL 60411
708)755-8030

actual 1
no

12. (12)
Marcia Wolff, Director of Work Services
Elim Christian School
13020 S. Central Ave.
Palos Heights, IL 60463
708) 389-0555

actual 2
yes

13. (13)
Michael Vandekreke,
Family Support Administrator
United Cerebral Palsy
311 S. Reed
Joliet, IL 60436
815) 744-3500

actual 1 (rep)
estimated 5
no

14. (14)
Gretchen Stanicek, Director
Early Intervention Program
Good Shepherd Center
2220 Carroll Parkway
Glossmoor, IL 60422
708) 957-5700

actual 1
yes (but impossible)

15. (15)

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Marianne Blair, Division Director
Spectrum - a Division of Little Friends, Inc.
2202 Wisconsin Ave.
Downers Grove, IL 60515
708) 852-7520

estimated 3 (rep)
yes

16. (16)
Karen Leonard,
Intake and Admissions Manager
Pioneer Center
4005 Dayton Street
Mc Henry, IL 60050
815) 344-1220

estimated 4 (rep)
yes

17. (17)
Maureen Martin, Intake Coordinator
Sertoma Centre, Inc.
4343 W. 23rd Street
Alsip, IL 60658
708) 371-9700

actual 4
no

18. (18)
Jane Hodgkinsa, Director
Western DuPage Special Recreation Association
671 Crescent
Glen Ellyn, IL 60137
708) 790-9370

estimated 10 (rep)
yes

19. (19)
Richard Winchell, Ed.D., Program Coordinator
LaGrange Area Department of Spe. Edu.
1301 West Cossitt Avenue
LaGrange, IL 60525
708) 354-5730

estimated 9 (rep)
no

20. (20)
Maryanne Dzik, Program Director
Parent Infant Program
Little Friends, Inc.
1001 E. Chicago Ave.
Naperville, IL 60540
708) 305-4196

actual 2
yes

21. (21)
James Lehmann,
Vice President-Program Services
Pare
9999 Roosevelt Rd., Suite 101
Westchester, IL 60154
708) 547-3550

actual 1
yes

22. (22)
Dennise II Spurr, Case Manager
Easter Seal
Easter Seal Rehabilitation Center

estimated 3
no

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212 Barney Drive
Joliet, IL 60435
815) 725-2194

23. (23)
Chris Lauffer, Director of Program Services — estimated 5 (rep)
Epilepsy Foundation of Greater Chicago — yes
20 E. Jackson blvd., suite 1300
Chicago, IL 60604
312) 939-8622

24. (24)
Thomas Pendelszewski, Program Director — actual 3
Bridge High School, Little Friends, Inc. — Yes
2318 Wisconsin Ave
Downers Grove, IL 60515
708) 964-1722

25. (25)
Joyce A. Morimoto, Technology Director — actual 1
National Lekozek Center — no
2100 Ridge Avenue
Evanston, Il 60201

26. (26)
Donna Fisher, — actual 5
Director, Adult Day Services**** — yes
Clearbrook Center
2800 W. Central Rd.
Rolling Meadows, IL 60008
708) 632-0700

27. (27)
Carolina Castanos-Sanz — actual 10
Social Servcie Department — yes
Augustana Center
7464 N. Sheridan Road
Chicago, IL 60626
312) 973-5200

28. (28)
Michael Wartman — actual 2
Director, Community Programs — yes
Lutheran Social Services of IL/Augustana Program
4433 W. Touhy #365
Lincolnwood, IL 60646
708) 329-0960

29. (39) *
Elizabeth Romo, — actual 5
Early Intervention Program Coordinator/ — yes
Child Development Specialist
Illinois Masonic Early Intervention Program
3048 N. Wilton
Chicago, IL 60657

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312) 296-7340

30. (40)
Marie Steen, Program Coordinator — actual 1
Glenkirk Campus — no
27255 N. Fairfield Rd.
Mundelien, IL 60060
708) 526-2176

31. (42)
Barbara Townsend, Vice President — actual 2
(Info received from staff therapist & case manager) — no
Mercy Hospital and Medical Center
Stevenson Expressway at King Drive
Chicago, IL 60616
312) 567-2000

32. (45)
Mary E. Toole, Program Director — actual 1
Home Infant Stimulation Program of LSSI — (2 AA on client waiting list)
5225 N. Ashland, GRD FLR, Rear — yes
Chicago, IL 60640
312) 275-5559

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Appendix 4

Asian Human Services of Chicago, Inc.

4753 N. Broadway Ave., • Suite 632, Chicago, Illinois 60640 • (312) 728-2285 • Fax (312) 728-4751

December 12, 1995

Rev. Sang Bok Lee
Chicago Marriage and Family Center
3214 W. Lawrence Ave
Chicago, IL 60625

Dear Director:

Under a grant from the Illinois Planning Council on Developmental Disabilities, Asian Human Services of Chicago is conducting a needs-assessment for people with developmental disabilities in the Asian-American community. This needs-assessment project aims to understand the prevalence of these disabilities, the current status of service utilization, difficulties and barriers encountered by these individuals and their families, and special needs for services. The results of this project will help develop programs tailored to the special needs of the Asian-American community and offer expanded services to those who currently are under utilizing them.

Enclosed is the survey questionnaire which was developed as a part of this process to estimate the number of Asian-Americans with developmental disabilities who are currently utilizing services. Unfortunately, there is no information available in the literature on the current prevalence of developmental disabilities in Asian-American community. That is why your participation in this survey is critically important to us because the information you provide will serve to estimate the current prevalence rate of developmental disabilities among Asian-Americans.

We would greatly appreciate it if you would be willing to participate in this survey process. The questionnaire is designed to be answered by someone at your agency who is able to provide specific information about the Asian-American clients with developmental disabilities including the type of disability, ethnicity, gender, and so on. The person who has some direct experiences working with these clients might be suited for answering the questionnaire. Please take a few minutes reading the questionnaire and transfer it along with the enclosed letter to someone who provides services to or has direct contact with these clients at your agency so that he or she could respond to the specific questions asked. If it is necessary to provide some information in your language or if you feel more comfortable answering questions in your language, please complete the questionnaire with your language. We have ethnically diverse bilingual staff members to understand your language.

We understand that your time is valuable and that you have a busy schedule. However, without your assistance, this project is not possible. Your participation enables us to identify how many people are affected by developmental disabilities and to understand difficulties and problems distinct to them and their special needs for services. The results of this project will help to develop culturally-suited service programs for the individuals with these disabilities and their families in the Asian-American community. We will greatly appreciate it if you would take time to forward the questionnaire for completion and have it returned in three weeks, approximately by the end of December. Please feel free to contact us if you have any questions or information relevant to this project. Thank you in advance for your interest and participation in this project.

Sincerely,

Keum Choi, M.S
Primary Investigator

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Survey of Asian-Americans with Developmental Disabilities

Name of Your Agency: _____
Phone Number of Your Agency: (_____) _____
Address of Your Agency: _____
_____
_____
Ethnic Groups Served by Your Agency: _____
Services Provided by Agency: _____
_____
_____
Name of Person Completing Survey: _____
Your Position or the Job Description: _____

1. The State of Illinois defines **developmental disabilities** as any disability which is attributable to mental **retardation, cerebral palsy, epilepsy or autism**. Does you agency provide any type of services to those with developmental disabilities? Please check one.

Yes _____ No _____

1. Asian-Americans are broadly defined as those whose families are from China, Taiwan, Korea, Japan, Philippine, India, Pakistan, Thailand, Hmong, Lao, Vietnam, Inconesia, Malaysia, Hong Kong and so on. Does your agency have Asian-American clients with developmental disabilities who are <u>currently</u> utilizing services at your agency? Please check one.

Yes _____ No _____

1a) If your answer was Yes, how many Asian-American clients with developmental disabilities are currently utilizing services from your agency. Please indicate either the estimate or the actual number which is available to you.

Number of Asian-Americans with developmental disabilities at your facility: _____
The above number is _____ actual
_____ estimated
(please check one)

2. Provided on the next page is a guideline for filling out some **non-confidential** information we need to know about your Asian-American clients with developmental disabilities. Following the example provided, please indicate specific information regarding clients with developmental disabilities who are currently utilizing services at your agency. Fill out as much as information available to you for each client. (Please use the back side if additional space is necessary). **Confidentiality of the clients is secured. It is not necessary to provide the clients' name**. Please refer to the instruction and example sections before attempting to complete the form. We are planning to have focus **group meetings** with some Asian-Americans with developmental disabilities and their families in order to gain some understanding about their spacial needs for support and service. The group consists of 3 or 4 families with a developmentally disabled member and requires approximately an hour participation. The participating families are provided with $20.00 as the token of appreciation for their sharing. Would you be willing to forward this information to families of your clients whom you might be willing to participate in a focus group?

Yes _____ No _____

If yes, you will be contacted regarding planning of focus groups.

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Client Report Form

CLIENT #	AGE OF CLIENT	GENDER OF CLIENT	ETHNICITY OF CLIENT	TYPE OF DISABILITY	SEVERITY OF DISABILITY	SERVICES RENDERED
Instruction		f: female m: male	Chinese Taiwanese Korean Japanese Filipinos Indian Pakistanian Thai Hmong, Lao Vietnamese Indonesian Malaysian other (specify)	mr: mental retardation cp: cerebral palsy a: autism e: epilepsy other (specify)	IQ mild: 50-70 moderate: 30-50 severe: below 30	describe the services rendered to the client
Example:	*14*	*m*	*Chinese*	*mr*	*moderate*	*vocational training*
Client #1						
Client #2						
Client #3						
Client #4						
Client #5						
Client #6						
Client #7						
Client #8						

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II. We would like to know whether there are any other formal or informal social support groups or service programs provided to those with developmental disabilities in your ethnic community. Are you aware of any of these organizations, agencies, or support groups in your community? Please check one.

_____ Yes, I know of such programs in our community.
_____ No, there are no such programs in our community.
_____ I am not sure whether or not such programs exist in our community.

If your answer was Yes, would you please share with us information about such service programs? Please describe the service programs or support groups including the name of the organization or a person in charge, telephone number, the purpose of the group, and the size of the group.

NAME	TELEPHONE NUMBER	PURPOSE OF GROUP	SIZE OF GROUP

III. Based on your past or current working experiences as a service provider, what kinds of issues or difficulties do those with developmental disabilities and their families have that are related to the ethnic/cultural background of your community? Please describe them.

IV. What kinds of particular needs do you think the developmentally disabled individuals might have as a result of their culture and ethnicity? How do you think those needs can be addressed? Please feel free to indicate any suggestions or recommendations for more effectively working with and reaching out them.

Thank You Very Much for Your Interest and Participation in This Project.

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Appendix 5

Asian-American Community Service Agencies (January-February 1996)

Respondents (Name/Position) Address/Phone #	Ethnic Groups Served/Services Provided	# of Clients with DD
1. Qua Tran, Senior program counselor Vietnamese Association of Illinois 5252 N. Broadway 2 Fl. Chicago, IL 60640 312) 728-3700	Vietnamese Information, referral, translation	Actual 8 Estimated 20
2. How Yee Cheng, Program Manager Chinese American Service League 310 W. 24th Place Chicago, IL 60616 312) 791-0418	Asian (Chinese) Counseling, health, youth center, peer education, cultural retention program elderly services	Actual 5
3. Sue Kang, Executive Director Korean American Senior Center 4750 N. Sheridan Suite 400 Chicago, IL 60640 312) 878-7272	Korean Supplementary education, in-home support services, employment, crime prevention/victim assistance, cultural recreational program, case management, home-based csm	Actual 4 Estimated 5
4. Abha Pandya, Executive Director Asian Human Services 4753 N. Broadway Suite 632 Chicago, IL 60640 312)728-2235	Asian Mental health counseling, job counseling and placement, Intergroup relations advocacy, community Education and legal services, low income energy assistance, seminars for single mothers, elderly services, HIV/AIDS education	Actual 6 Estimated 11
5. Kompna Seth, Director Cambodian Association of Illinois 1105 W. Lawrence Ave.2nd Fl. Chicago, IL 60640 312) 878-7090	Cambodians Employment, cultural adjustment	None
6. Sumnan Kubose, Executive Director Japanese American Service Committee 4427 N. Clark Chicago, IL 60640 312) 275-7212	Hispanic, Taiwanese, Japanese, Chinese, African-American Adult day care, home chore service, social work/case management	None
7. Dhondup N. Gonsar, Director Tibetan Alliance of Chicago 4750 N. Sheridan Rd. Suite #419 Chicago, IL 60640	Tibetan Physical health, education, community development, employment, advocacy	None

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312) 275-7454

8
Hong Liu, Ph.D., Center Director
Immigrant/Refugee Area Health Education (AHEC)
4753 N. Broadway, Suite 500
Chicago, IL 60640
312) 275-4773

All
Youth career program, health resource center, community-based health programming, professional educational & technical services

None

9
Joanne Lee, Psychosocial coordinator
Ambassador Nursing & Rehabilitation Center
4900 N. Bernard
Chicago, IL 60625
312) 583-7130

None

10
Jae K. Ha
Counseling Center for Senior Citizens
4753 N. Broadway Suite #708
Chicago, IL 60640
312) 275-4989

None

11
Cesar Vsero Ubacoe,
Case Manager,
Food Service-Project Coordinator
Asian American AIDS Foundation
4750 N. Sheridan #429
Chicago, IL 60640
312) 989-7220

Japanese, Chinese, Filipino, Lao Vietnamese, Cumbodian, Indian, African, Korean,
Case management; referral, AIDS, food service

None

3 returns

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Appendix 6

Asian Human Services of Chicago, Inc.

4753 N. Broadway Ave., • Suite 632, Chicago, Illinois 60640 • (312) 728-2235 • Fax (312) 728-4751

WE INVITE YOU TO A GROUP INTERVIEW!

Dear Family:

Under a grant from the Illinois Council of Developmental Disabilities, Asian Human Services of Chicago is conducting a needs-assessment for people with developmental disabilities in the Asian-American community. The purpose of the project is to gain understanding about special needs of Asian-American developmentally disabled individuals and their families for support and services. The results of this project will help develop service programs sensitive to the special needs of the AsianAmerican individuals with developmental disabilities and their families.

A part of this project requires interviews in a group format with Asian-American families which ha our focus ve a developmentally disabled member. Hence we ask your assistance and invite you to our group interview meeting. Your participation enables us to identify and understand your concerns and needs for social support or services. Your information will help develop intervention programs which will improve the quality of life for you and other families with a developmentally disabled member.

To thank you for your assistance, we provide you with $15.00 as the token of appreciation for your participation. If you are interested in participating in this group meeting, please indicate your willingness to the person who gave this information to you, who will inform me later of your decision. Or, you could also call me directly, Keum Choi, at 312/728-2235 at the Asian Human Services to discuss about your interest. If I am not available, please leave your name and phone number with the secretary so that I could reach you at your convenience. The following is some information about a group interview you might want to know prior to making a decision:

Procedure

About What: 1. Discussion about issues or difficulties you have experienced in the past and are currently experiencing while taking care of your child or family member with a developmental disability.
2. Discussion about needed social support or services

With Whom: Keum Choi (interviewer) and 3 or 4 other families with a developmentally disabled child or family member.

How Long: 1 hour-long participation

Which Language: Your preferred language (Translators are available)

What Date and What Time: At your convenience

Where: At your convenience

If you have any further questions about this group interview, please feel free to call me. Keum Choi, (312) 728-2235, Asian Human Services of Chicago.

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Appendix 7

Survey of Asian-Americans with Developmental Disabilities and Their Families

Asian Human Services is assessing what kinds of difficulties Asian-American developmentally disabled individuals and their families are experiencing when trying to gain access to social services, and what kinds special social support and services are needed for better quality of life. We would appreciate it if you would answer the following questions.

I. **Information about your family**

1. What is your relationship to the person (child) with developmental disabilities?

_____ Mother
_____ Father
_____ Grandmother
_____ Grandfather
_____ Step Parent
_____ Relatives
_____ Other (Specify)

2. Other than the person with the disability, are there other persons living in your home who have disabilities?

_____ Yes _____ No
(Describe if yes, _____)

3. Including yourself, how many people live in your household? _____

4. Which of the following describes your household?

_____ Two parents in the house
_____ Single parent household
_____ Living with relatives
_____ Foster home
_____ Shared household with persons other than family
_____ Other (Specify)

5. Who would you identify as a *primary care taker* for the person with DD? _____

6. What is your ethnic background? _____

7. Which language do you prefer to speak? _____

8. How would rate your English proficiency? (Circle the number best describes the answer)

Very poor	Poor	Moderately Fluent	Fluent	Very Fluent
1	2	3	4	5

9. What is the occupation of the head of your household? _____

10. What is your family's annual income?

_____ None
_____ Under $5,000

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_____ $5,001 - $10,000
_____ $10,001 - $15,000
_____ $15,001 - $20,000
_____ $20,001 - $30,000
_____ $30,001 - $40,000
_____ $40,001 - $50,000
_____ Above $50,000

II. Information about the person with DD

1. Which disability does the person with DD have?

_____ Mental retardation
_____ Epilepsy
_____ Autism
_____ Cerebral palsy
_____ Other disabilities (Specify, _____)

2. How severe is the disability?
_____ Mild
_____ Moderate
_____ Severe

3. What is the birth date of the person with DD?

Year _____ Month _____

4. Gender _____ Male
_____ Female

5. What is the person with DD's ethnic background? _____

III. Service Information

1. Which agencies and what kinds of services has/had the person with DD contacted in the past? (Check all that apply)

_____ Department of Children and Family Services (DCFS)
_____ Department of Rehabilitation Services (DORS)
_____ Department of Mental Health and Developmental Disabilities
_____ Department of Corrections (DOC)
_____ Department of Public Health (DPH)
_____ Early Education Services
_____ Division of Special Care for Children
_____ Juvenile courts of Police Department
_____ Church or privately sponsored social service agency
_____ Local or community mental health agency
_____ Public housing
_____ Special recreation Program
_____ Other, specify _____
_____ None

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2. Does the person with DD receive government benefits from any of the following agencies (Check all that apply). Also, which year did the services begin?

	Year Service Began
_____ Supplemental Security Income (SSI)	_____
_____ Medicaid	_____
_____ Social Security Administration (SSA)	_____
_____ Public Aid/Welfare (AFDC)	_____
_____ Division of Services for Crippled Children (DSCC)	_____
_____ Other (Specify, _____)	_____
_____ None	

3. Which types of care and services does the person with DD and your family need? (Circle the number which best describes the answer.)

Housing Alternatives	No Need				Most Needed
1. Skilled nursing (over age 15)	1	2	3	4	5
2. Specialized care facility for DD	1	2	3	4	5
3. Residential school	1	2	3	4	5
4. Community group home (adults)	1	2	3	4	5
5. Foster care (children)	1	2	3	4	5
6. Supported independence living	1	2	3	4	5
7. Assistance with care at home (by family)	1	2	3	4	5

Day Programs	No Need				Most Needed
1. In-home infant stimulation (0-3)	1	2	3	4	5
2. Preschool (3-5)	1	2	3	4	5
3. Special education (K-12)	1	2	3	4	5
4. Adolescent/Adult vocational programs	1	2	3	4	5
5. Sheltered workshop	1	2	3	4	5
6. Activity program	1	2	3	4	5

Other Services	No Need				Most Needed
1. Medical Care:	1	2	3	4	5
Speech therapy	1	2	3	4	5
Physical therapy	1	2	3	4	5
2. Dental Care	1	2	3	4	5
3. Specialized equipment/supplies	1	2	3	4	5
4. Counseling/therapy	1	2	3	4	5
5. Leisure activities/special recreation	1	2	3	4	5
6. Specialized summer camp	1	2	3	4	5
7. Transportation	1	2	3	4	5

Services for Families (Care givers)	No Need				Most Needed
1. Respite care	1	2	3	4	5
2. Case management (Advocacy)	1	2	3	4	5
3. Translators	1	2	3	4	5
4. Family education/training about DD	1	2	3	4	5
5. Transportation	1	2	3	4	5

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